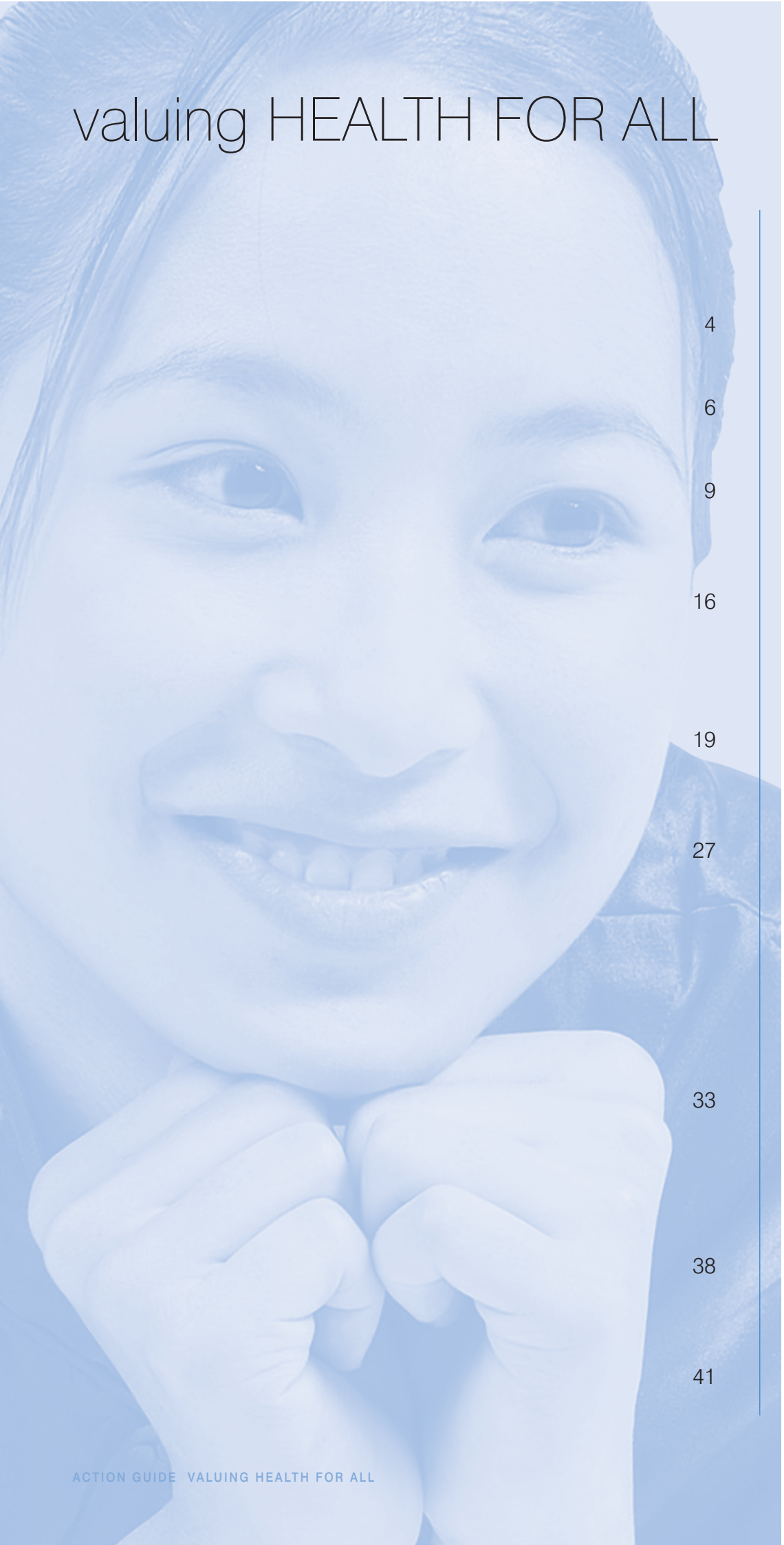
valuing HEALTH FOR ALL



contents

foreword

by David Colin-Thomé

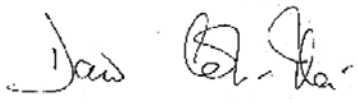
Better health and better health services – these are the promises in the NHS Plan.

Good health is everybody's wish and everybody's business, but PCTs have a particular responsibility for people who are at extra risk of poor health and poor access to health services. The White Paper *Valuing People* drew attention to the health inequalities experienced by people with learning disabilities. The subsequent good practice guidance *Action for Health* set out ways of improving both individual and population health.

This Action Guide is based on experience over two years in 12 areas and shows, with many practical examples, how PCTs can address the health needs of people with learning disabilities both strategically and in day-to-day service delivery.

I know that PCTs, practices and other NHS services are faced with many pressing priorities. Sometimes it can seem as though the needs of people with learning disabilities are presented as yet one more on the list. It is encouraging that in so many of the project sites people were successful in bringing a learning disability perspective to existing priorities, such as implementing National Service Frameworks, with resultant improvements for everyone who uses services.

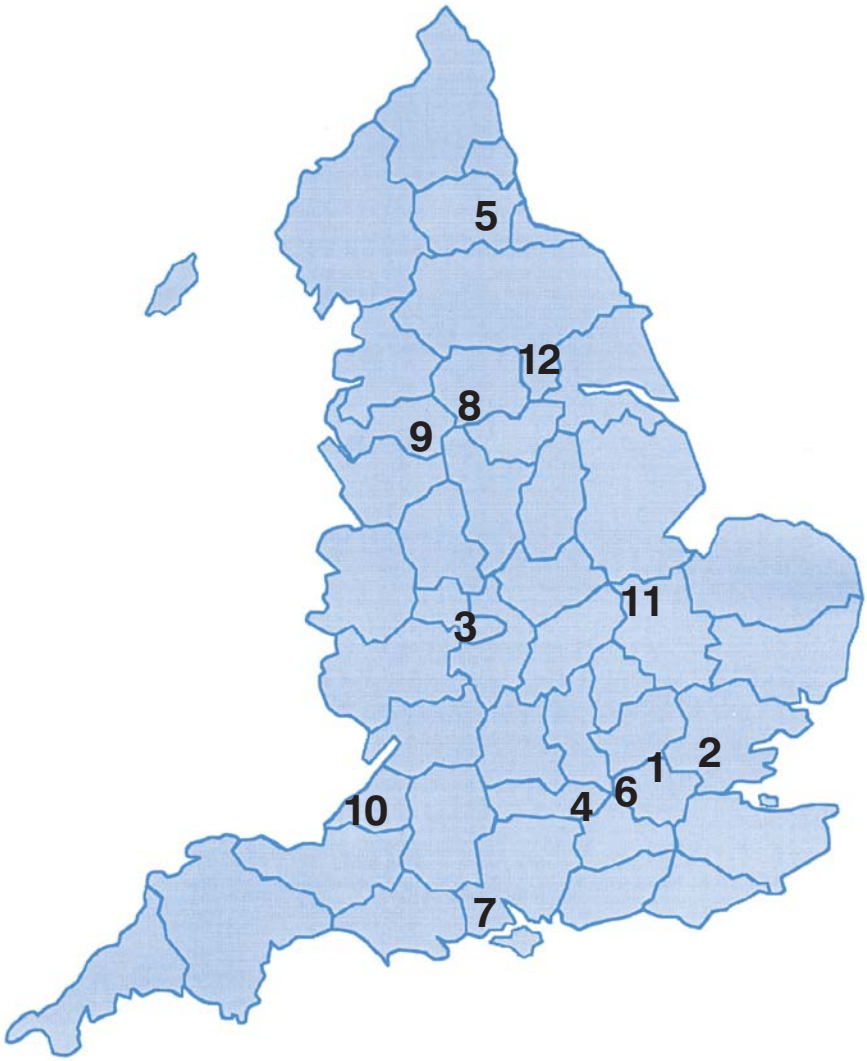
Achieving such improvements does require both leadership and some development capacity. The ideas and examples in the Action Guide show how the knowledge and expertise of people with learning disabilities themselves and of specialist learning disability staff can help PCTs to deliver and commission better services. I strongly and enthusiastically commend it.



David Colin-Thomé,

National Clinical Director for Primary Care

project sites



areas

1 Barnet

2 Billericay, Brentwood and Wickford

3 Birmingham

4 Bracknell Forest

5 Durham & Darlington

6 Hammersmith & Fulham

7 Hampshire

8 Kirklees

9 Manchester

10 North Somerset

11 Peterborough

12 York

summary

an invitation

Valuing Health For All

Current national policies and local delivery plans offer the chance of better health for everyone and a step-change in the quality of health services. Primary Care Trusts have the key local role in ensuring this happens for all in their populations. People with learning disabilities have relatively poor health compared with their fellow citizens and often experience less good access to appropriate services.

This Action Guide is addressed primarily to:

- **Executive leadership in PCTs**
- **Senior staff with specific learning disability leadership roles**
- **Primary care teams**
- **Community staff with learning disability expertise**
- **People with learning disabilities and others engaged with them in health advocacy**
- **PCT partners in the Learning Disability Partnership Boards and Strategic Health Authorities**

Drawing on the lessons from recent experience in 12 PCTs across England, it offers these readers an invitation to work together to ensure people with learning disabilities are part of the *all*.

Current national policies for health and health services, set out most clearly in ***The NHS Plan***, the Priorities and Planning Framework 2003-2006 ***Improvement, Expansion and Reform*** and the growing list of ***National Service Frameworks*** offer great opportunities and also significant challenges to the local agencies and their staff with responsibilities for implementation.

Working with a wide range of partners, Primary Care Trusts (PCTs) have the major local leadership role in ensuring these opportunities are used to best effect for their populations. Good health is of course 'everybody's business' but PCTs are key to progress through their roles as:

- champions for health;
- shapers of all the health services provided to local people; and
- providers with General Practitioners and staff of high quality primary and community services.

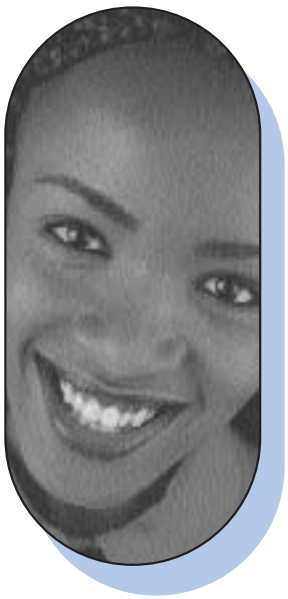
The NHS is based on a fundamental commitment to equity and public accountability. The national priorities put a premium on tackling health inequalities and ensuring fair access to appropriate services. PCTs have a lead role therefore in improving health and health services to disadvantaged people in local communities.
There are of course many sources of disadvantage: poverty and social exclusion, prejudice and discrimination, environmental conditions which are damaging to mental or physical health, etc. Equally, there are many ways of identifying target groups who suffer these disadvantages. PCTs need to find the best ways of addressing the health challenges associated with disadvantage across *all* their populations.

This **Action Guide** focuses on including one major disadvantaged group, people with learning disabilities, but with what we believe are more general lessons. As the Prime Minister says in his Foreword to the recent national learning disability strategy *Valuing People*:

> *'People with learning disabilities can lead full and rewarding lives as many already do. But others find themselves pushed to the margins of our society. And almost all encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives.'*

They are more likely to have:

- poor health compared with other people;
- greater difficulty in accessing services others use; and
- more negative experiences of using health services.



Valuing People estimates that there are around 210,000 people with severe learning disabilities and more than 1.2 million people with mild/moderate learning disabilities in England i.e. on average about 8 people with severe, and 50 with mild/moderate, learning disabilities in a practice list of 2000.

With support from the Department of Health, a team from King's College, London identified 12 areas based on Primary Care Groups, now PCTs, spread across England as shown in the map, where there was an expressed interest in trying to ensure that the needs of people with learning disabilities are addressed as part of the delivery of current mainstream policies i.e. that they are part of the ***all***. We have worked with these 12 sites over the past 18 months to :

- assist in local efforts to improve health and health services to this disadvantaged part of the population;
- help those involved learn from each other across the 12 sites;
- draw wider lessons for including people with learning disabilities in delivery of the Priorities and Planning Framework.

Using experience and examples from the 12 sites, this Action Guide provides a succinct account of the lessons to date, addressed to all the key stakeholders involved in making local progress. In all the PCTs which joined the project, this remains work in progress. What we report here are intelligent approaches, key steps, early successes and promising directions of further travel – not a comprehensive 'blueprint'.

Nevertheless we believe the discussion of key issues in the four Chapters which follow and the ***Action Checklist*** at the end offer useful practical advice to local leaders across England who are rising to the challenge of ensuring ***All means all***.

The diagram over leaf illustrates the shape of our analysis and provides a summary of key lessons, developed further in the text which follows.

summary KEY FINDINGS

Goals

Ensuring people with learning disabilities are included alongside other local citizens in local strategies to:

IMPROVE PATIENT ACCESS

DELIVER BETTER SERVICES AND OUTCOMES

IMPROVE THE EXPERIENCE OF SERVICE USERS

REDUCE HEALTH INEQUALITIES

STRENGTHEN NHS CAPACITY

ENHANCE NHS LOCAL ACCOUNTABILITY

DEVELOPING PCT CAPACITY

- Planning with Learning Disability Partnership Board allies
- Establishing senior internal leadership for the health of people with learning disabilities
- Including the needs of people with learning disabilities in NSF and other local health improvement strategies
- Using staff with learning disability expertise to promote mainstream inclusion
- Ensuring routine information systems track learning disability health issues
- Investing in practitioner and staff training for inclusive practice
- Strengthening two-way communication with people with learning disabilities and their families

INVOLVING PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

Improving peoples' health and health experience through:

- Ensuring registration for all with a GP and dentist
- Providing easy to understand health information
- Offering individuals their own Health Action Plan
- Fostering appropriate and respectful treatment

Listening to the views of people with learning disabilities and their families through:

- Surveying their health experience
- Supporting health advocacy
- Engaging people with learning disabilities in staff training and service audit

ADDRESSING THE HEALTH FOR ALL AGENDA IN MAINSTREAM SERVICES

- Addressing health inequalities in partnership with others
- Collecting and using data about health of people with learning disabilities
- Including a learning disability perspective in NSFs and Cancer Plan implementation
- Surveying access to health services and acting on the results

RESHAPING SPECIALIST CONTRIBUTIONS FROM COMMUNITY LEARNING DISABILITY TEAMS

Reviewing community teams and the roles of specialist health professionals and:

- balancing individual interventions with help for other services to do their jobs better
- ensuring specialists work with mainstream health services *and* learning disability services
- developing the health facilitation role
- supporting the introduction of health action plans.

developing PCT capacity

PCTs and Their Local Partners: Working Together for Health

The ***NHS Plan*** and subsequent policy documents set out the duty of health services and local authorities to work in partnership to improve the health and well-being of their populations; PCTs are expected to be the local leaders for:

- improving health
- shaping all local health services
- providing good primary and community health services.

National policy evolved during the life of the project, strengthening the role of PCTs. Their current responsibilities are laid out in the Priorities and Planning Framework 2003-2006 ***Improvement, Expansion and Reform***. Local Delivery Plans are expected to bring together planning to meet both national and local priorities. National priorities have been set under the following headings:

- improving access to health services
- better services and outcomes
- improving the overall experience of users of health services
- reducing health inequalities
- increasing capacity to meet needs
- improving local accountability of the NHS.

Support for PCTs to develop in their new roles is offered by the National Primary & Care Trust development team (NatPaCT), who have developed a competency framework and development materials for PCTs. The learning from this project will be incorporated in future revisions of the framework.

summary

Primary Care Trusts (PCTs) have a lot of important things to do to help local people have better health and better health services. This includes people with learning disabilities. PCTs can make sure they are ready to do this by:

- **working closely with other agencies in the Learning Disability Partnership Board;**
- **having a senior person (or people) to take a special interest in the health of people with learning disabilities;**
- **making sure people with learning disabilities are included in what PCTs have to do for everyone, like improving care for people with heart disease or cancer;**
- **asking staff with learning disability expertise to help PCTs, GPs and other health professionals to include people with learning disabilities;**
- **getting and using good information about the health of people with learning disabilities;**
- **investing in training for PCTs, GPs and other health professionals;**
- **being informed by the experience of people with learning disabilities, their families and advocates.**

developing PCT capacity

project experience

Some PCTs engaged actively with the health inequalities agenda, accepting responsibility for the general health of people with learning disabilities and recognising the skills offered by specialist staff. In some other areas PCTs were immersed in restructuring and trying to meet the national 'must do' priorities and were less receptive to approaches from the learning disability 'world'.

The project sites looked for ways of building on the opportunities and managing the challenges. In particular, they sought to:

- engage the interest of PCT leaders and identify 'champions' amongst both clinicians and managers
- link concerns about the health of people with learning disabilities into the mainstream PCT priorities and activities
- bring a learning disability presence and contribution to PCT activities
- engage with the concerns of mainstream health practitioners and help to devise solutions
- equip the PCT, its staff and independent contractors for informed action
- learn from early efforts at all these things about what is required to develop the capacity of PCTs to be more effective in the next two to three years.

There are four main routes for PCTs to tackle health improvement for people with learning disabilities – by ensuring, with their partners, that a learning disability perspective is included in:

- the health improvement focus of Local Strategic Partnerships
- commissioning arrangements for health services from hospitals and other NHS Trusts
- direct provision of primary and community health services

and that a health perspective is included in the work of the Learning Disability Partnership Board and joint or lead commissioning arrangements with the local authority.

The new GP contract was being discussed as this project concluded, so its potential impact is not yet clear, but it may offer a mechanism for PCTs to develop enhanced services that would encompass some of the ideas in the rest of this workbook.

Leadership for health

In two sites, involvement in the project was initiated by the PCT Chief Executive; in another, learning disability specialist services moved into the PCT from an NHS Trust. In others learning disability leaders tried a variety of ways of engaging interest. For example:

- supporting self advocates to approach PCT leaders such as the chair and chief executive
- identifying practices with a large population of people with learning disabilities and contacting the practice manager and a GP or a district nurse
- finding an interested member of the Professional Executive Committee (PEC), or getting someone with a learning disability background elected to the PEC.

The leadership role may be addressed across a number of PCTs – with one taking a co-ordinating role. The common factors for success in addressing the health of people with learning disabilities were development capacity backed by senior commitment.

PCTs need a nominated 'lead' person with dedicated time to take forward the learning disability agenda, as well as support from senior 'champions'. A key role for a 'lead' person is to harness the skills and capacity of others. Even if commissioning of specialist services is delegated, the PCT retains responsibility for ensuring that mainstream health services are responsive to the needs of people with learning disabilities and it can help ensure that other services pay attention to health issues.

EXAMPLE **Bracknell Forest PCT's chief executive initiated their involvement in the project and was a strong supporter throughout, keeping the profile of learning disability issues high and using development funding to support a project post. This combination of development capacity and top management commitment proved very effective. In another site with no PCT 'lead' it was more difficult to achieve change; however, some progress was made through 'championing' by a local GP both on the PEC and on the learning disability Partnership Board. Barnet PCT's chairman, chief executive, locality chair (a GP) and locality manager all made time to meet people with learning disabilities and pay attention to their issues.**

EXAMPLE **In Billericay Brentwood & Wickford the PCT chief executive and lead GP arranged a seminar on learning disability for the PCT Board; this PCT then took the lead on behalf of others in the area to commission specialist learning disability health services. This required clarification about the other PCTs' responsibilities for ensuring access to general health services.**

developing PCT capacity

Linking into the mainstream

Valuing People is explicit in its expectation that people with learning disabilities should be supported to gain better access to mainstream services – and that mainstream services should be supported to become more inclusive. *Improvement, Expansion and Reform – ensuring that 'all' means 'all'* expands on this and includes many ideas and suggestions for PCTs and primary health care teams to consider.

This theme was one of the strongest to emerge from the project sites. Making links depended in general on initiatives from learning disability managers and practitioners. They needed to:

- take time to understand mainstream priorities, targets, funding and language
- find the right forums and interested individuals
- maintain a presence even when the topics of meetings did not appear especially relevant
- persist!

There was anecdotal evidence from some sites that this was easier when staff with learning disability responsibilities were employed by the PCT. The time commitment to make such links was hard for sites that had limited development capacity.

PCT leaders, supported by learning disability specialists, need to ensure that people with learning disabilities are included in their mainstream priorities. Influencing practice in primary health care teams may require the involvement of different people and skills from those involved in broader policy development.

EXAMPLE **In Birmingham, learning disability practitioners joined NSF implementation groups. The Health Authority commissioning manager discussed with each PCT how to include the learning disability perspective in their Health Improvement & Modernisation Plan priorities. Manchester identified a senior learning disability nurse as project worker and she was successful in getting learning disability included in the Cancer Plan implementation, showing how this could help achieve the Plan priorities. Elsewhere progress was made through learning disability staff collaborating in the development of care pathways for common conditions.**

EXAMPLE **Learning disability staff in Barnet moved into the PCT (when the community NHS Trust dissolved), together with the Health Authority commissioner. They were able to contribute to and influence PCT activities both in a planned way (for instance through the normal planning cycle) and opportunistically via their presence in mainstream forums, such as commissioning, health development, clinical governance, and locality management. Between them they were able to spot and follow up opportunities to connect with mainstream priorities, such as improving access for people from minority ethnic groups, work on practice registers, and professional development.**

Learning disability contributions

Just as learning disability staff had to learn about mainstream priorities, targets, funding and language, so people working in PCTs and mainstream health services had the chance to find out about the skills that have developed in learning disability services. In some places learning disability staff, like the people they support, have been seen as marginal to NHS priorities and there have been misperceptions about their skills and activities. This has been exacerbated where learning disability specialists have in effect offered substitute services. Efforts to link with mainstream priorities, as described above, have enabled learning disability staff to show how they can help improve health services for everyone.

Learning disability practitioners and managers have valuable skills that are transferable to mainstream health settings and priorities.

EXAMPLE **Integrated working between health and social services has been in place for a number of years in Manchester's learning disability services. Through the project, the skills and knowledge gained from this experience are being shared with the Integrated Care Team in one PCT to promote integrated working for older people.**

EXAMPLE **Barnet's accessible information about screening for women with learning disabilities proved very popular with other women, such as those who were not confident readers or whose first language was not English. The initiative should help to improve the uptake of screening and women's experience of these services. The concept of person centred approaches was another 'idea transfer': PCT managers found that learning disability colleagues were able to help them think through a different approach to rehabilitation and support for people with physical disabilities, including stroke.**

developing PCT capacity

further information

The policy context for PCT development is set out in the four main Department of Health publications referred to in the text: *The NHS Plan: a plan for investment. a plan for reform* (2000) Cmnd. 4818-1. **www.doh.gov.uk/nhsplan/default.htm**; *Improvement, expansion and reform: the next three years. Priorities and planning framework for 2003-2006* (2002) **www.doh.gov.uk/planning2003-2006/index.htm**; *Valuing People – a new strategy for learning disability for the 21st century.* (2001) Cmnd. 5086 **www.official-documents.co.uk/document/cm50/5086.htm**; *Improvement, expansion and reform: ensuring that 'all' means 'all'* (2003) **www.doh.gov.uk/vpst**

The developments in PCT capacity described here can be set withn a wider 'competency framework' developed through the National Primary and Care Trust Development team and available in its latest form through the NatPaCT web-site **www.natpact.nhs.uk**

Guidance on Department of Health proposals for implementing health action planning and health facilitation for people with learning disabilities is set out in *Action for health – Health Action Plans and Health Facilitation. Detailed good practice guidance on implementation for Learning Disability Partnership Boards* (2002). **www.doh.gov.uk/learningdisabilities/healthactionplans.htm**

Addressing practitioners' concerns

Increased participation in mainstream health forums, combined with the attitude described above of listening and learning, enabled learning disability staff to hear about the concerns of practitioners in primary and secondary health care. These included, for example, concerns about:

- their own knowledge and skills
- communicating with people with learning disabilities
- consent to health interventions
- people coming to a surgery or hospital with poor information and poorly prepared supporters.

Valuing People required review of the role and functions of community learning disability teams, to ensure an appropriate balance between direct interventions and activities such as teaching and support for mainstream health services. Each person with a learning disability will be offered a Health Action Plan that identifies their health needs and the action required to support them. The development of a new role – health facilitation – is expected to help PCTs and health professionals to fulfil their responsibilities to people with learning disabilities.

Mainstream health practitioners may need reassurance that they are being asked to apply their professional skills to the health problems experienced by people with learning disabilities, not to 'treat' learning disability. Support from learning disability specialists should be designed collaboratively and may also involve work with self advocates, family carers and paid supporters to ensure that they know how to use health services and are well prepared.

EXAMPLE **GPs sometimes complain that people with learning disabilities turn up at surgeries with little or no information about their health problems and with supporters who do not know them well enough to support a meaningful consultation. Manchester developed *Guidelines to assist in achieving successful health consultations.* This can be used in conjunction with their *Maintaining health and well-being* document. The handbook provides a step by step guide to health consultations with health professionals such as GPs, hospital doctors, nurses, dentists, and optometrists. The handbook is 'owned' by the person with learning disability.**

EXAMPLE **Manchester also worked with hospitals to address their concerns about people attending A&E and about consent. The latter issue is now on the hospital clinical governance agenda.**

Equipping the PCT for informed action

Linking into mainstream health priorities, such as NSFs, is easier to do if there is good information about the health needs of people with learning disabilities and their experiences of using health services. Work on health inequalities and on NSF targets is increasingly driven by data on the PCT's population and groups within it. NHS funding is often targeted nationally at such priorities. To ensure that people with learning disabilities are included in such initiatives and benefit from the additional funding, it is essential to gather robust data that can be correlated with other health data (for example, heart disease registers). Clinical governance in relation to other conditions (e.g. epilepsy) also becomes easier if patients' records are correctly coded. As they develop, PCT information systems could also provide the basis for effective inter-agency registers, to support integrated working.

At present clinical computer systems used by GPs record data using the Read code system. The project found that different codes were used across the country to record learning disability. Several project sites (Birmingham, Peterborough and Hampshire) worked on clarifying the appropriate coding. The recommendation from the project is to use code E3. Although this is labelled 'mental retardation' because it is linked into international terminology, it is technically correct. The alternatives that some people have used are more appropriate for learning difficulties such as dyslexia. Help with clinical coding and data 'flags' as clinical tools across pathways and conditions can be obtained from the Primary Care Information Services (PRIMIS), a national support service, or the local information facilitators based in each PCT.

Both strategy and service delivery require the support of information systems to identify and track the health experiences of people with learning disabilities individually and as a population. There also needs to be early and continuing investment in training (breadth and depth) and other forms of 'awareness raising' about the health needs and experiences of people with learning disabilities. This should include practitioners such as dentists and optometrists. Involving people with learning disabilities as co-trainers can be particularly effective here.

EXAMPLE **Appropriate coding of learning disability (to allow retrieval of subsets of information) was explored with local PRIMIS facilitators. A recommendation was made to the NHS Information Authority that Read Code E3 should be redesignated 'learning disability' (instead of 'mental retardation') and that PCTs should be encouraged to use this code consistently. This would enable better data on the health of people with learning disabilities to be gathered and analysed. In York the Caldicott Guardian agreed to draw up a protocol to cover sharing of information between York PCT and the local authority.**

EXAMPLE **Training needs of GPs and other members of primary health care teams were identified both opportunistically and through attendance at forums such as those for practice nurses. It was then possible to deliver training valued by the participants, either via existing routes (such as the Protected Learning Time Forums in Manchester) or in specially arranged events at times that suited practices. Similarly, NHS Direct in Birmingham were trained and supported by learning disability staff to ensure that they could respond appropriately to enquiries from people with learning disabilities and their families.**

involving people

summary

National policies tell the NHS to make a priority of

- improving access to health services
- improving the health experience of patients, and
- improving the way they report to the public.

All this is very important to people with learning disabilities and their families. So:

- Primary Care Trusts must make sure local people with learning disabilities are informed about, and involved in, improving health.
- PCTs must take action to improve the health of individuals and their experience of health care.
- This includes making sure people with learning disabilities:
  - Are registered with a GP and dentist
  - Have a Health Action Plan if they want one
  - Get easy-to-understand health information and
  - Are always treated with respect.
- PCTs must also listen to the views of groups of people with learning disabilities and their families.
- This includes making sure that:
  - There are regular surveys of peoples' experiences of health and health services
  - Different types of advocacy are available locally
  - People with learning disabilities are employed in training staff and reviewing service quality.
- Different kinds of action are required to help PCTs to make good progress on these steps and show that, in health at least, people with learning disabilities are full citizens.

Involving People with Learning Disabilities and Their Families

Nothing About Us Without Us is the title which the national self advocate advisory group gave to their contribution to the *Valuing People* White Paper. This principle is a useful starting point for considering how the NHS can play its part in improving the health and health experiences of people with learning disabilities.

As *The NHS Plan* makes clear, better accountability to patients and the public is fundamental to NHS reform. *Improvement, Expansion and Reform*, the current Priorities and Planning Framework, and the related Public Service Agreement express this objective in the requirements on the NHS to:

> ***'ensure that people are fully informed and involved in their own care and in planning and reviewing services';***
>
> ***'review (its) arrangements for involving and communicating with all (its) stakeholders'; and***
>
> ***'secure sustained national improvements in patient experience as measured by independently validated surveys'.***

This public policy commitment to accountability and involvement is part of a more general rationale for engaging service users. This is based on the arguments for helping people get more control over their lives set out in *Valuing People* and recognition that in health, as in many other areas of life, services are likely to be more effective if delivered in partnership with the intended beneficiaries. The action required here relates both to the *individual* experience of health and health services and to *collective* arrangements for enabling communities to shape and monitor health services.

This is important to all of us. It is especially important to people with learning disabilities given the accumulated evidence of both their poorer than average health and relatively poor access to and experience of health services. If PCTs and their local partners are to deliver on this commitment, they need therefore to give special attention to communication with and involvement of people with learning disabilities and their families. They need to recognise the extra challenges that may be involved in relation to people who have historically been the subject of extensive discrimination. Conversely, it is essential that these extra challenges do not become the excuse for continued discrimination.

The reference here to people with learning disabilities and their families recognises that both for children and also for many adults (especially those with greatest needs for support), other family members often remain not only those who know people best but also the only continuing members of their support networks. Public services need to recognise this reality while making every effort to listen directly to people with learning disabilities. The lessons from experience which follow focus especially on the direct engagement of people with learning disabilities.

A broad agenda for change

Experience in the project sites suggests PCTs and their partners need to take action across their populations to:

- Identify people with learning disabilities (e.g. those known to specialist learning disability services) and ensure all are registered with general practitioners and dentists of their choice;
- Ensure these people and their supporters have access to a variety of forms of accessible information (Health Education sessions; 'Books Without Words', Personal Health Information files) about health and health services;
- Enhance professional awareness and skills (e.g. in general practice) in delivering services to people with learning disabilities;
- Enable everyone who wants this to have a Health Action Plan and good support ('Health Facilitation') in developing and implementing it.
- Establish Patient Advice and Liaison Services (PALS) which both understand and are good at responding to issues raised by people with learning disabilities and their families;
- Invest in strengthening independent advocacy for people with learning disabilities (e.g. the sources known to PALS staff).
- Make systematic efforts to listen to the views and experiences of people with learning disabilities and their families (e.g. through appropriate methods in the annual surveys) including in black and ethnic minority communities; and
- Strengthen the collective voice of people with learning disabilities on health issues (e.g. in Patient Forums, learning from experience in the Learning Disability Partnership Boards) and ensure their direct involvement in service development, staff training and quality assurance activities.

If this range of activities is to gradually address and include the full range of people with learning disabilities, PCTs will need to mobilise a variety of local contributors, including commissioning leads, primary care development staff, health promotion and learning disability health specialists, PALS officers and front-line staff willing to take on a 'champion' role in their services. They will also need to support and work with self advocates, families and local people with skills in providing independent support to people with learning disabilities. A significant leadership function therefore is to link this list of tasks to regular mapping of who is well-placed to take the required action.

Making it happen

The picture on the followoing page comes from a national conference on ***Speaking Up For Health*** which brought together self-advocates and staff leaders from across the project sites. Taken together the elements in the picture start to map what this stronger involvement of people with learning disabilities (they often prefer the term 'people with learning difficulties') needs to look like as PCTs set out to ensure their accountability to patients and the public, in the spirit of ***All Means All.***

further information

The best general guide to involving people with learning disabilities in improving services is *Deciding Together*, published in 2001 and available from King's College, London, Centrevents (Tel.**0207 848 3740**).

The more accessible version of this guide is *Getting Control of My Life* available from the same source.

The Department of Health has published (2002) accessible guides (both written and on tape) to Health Action Plans *Health Action Plans, What are they? How do you get one?* Available from Department of Health Publications (Fax **01623 724524**).

The best series of accessible books on health issues are the Books Beyond Words published by Gaskell and St. George's Hospital Medical School, further information from the Royal College of Psychiatrists (Tel. **0207 235 2351**).

The leading social firm (employing people with learning disabilities) engaged in helping with the development of accessible communication is *Working With Words*, more information at **workingwith@words01.fsnet.co.uk**

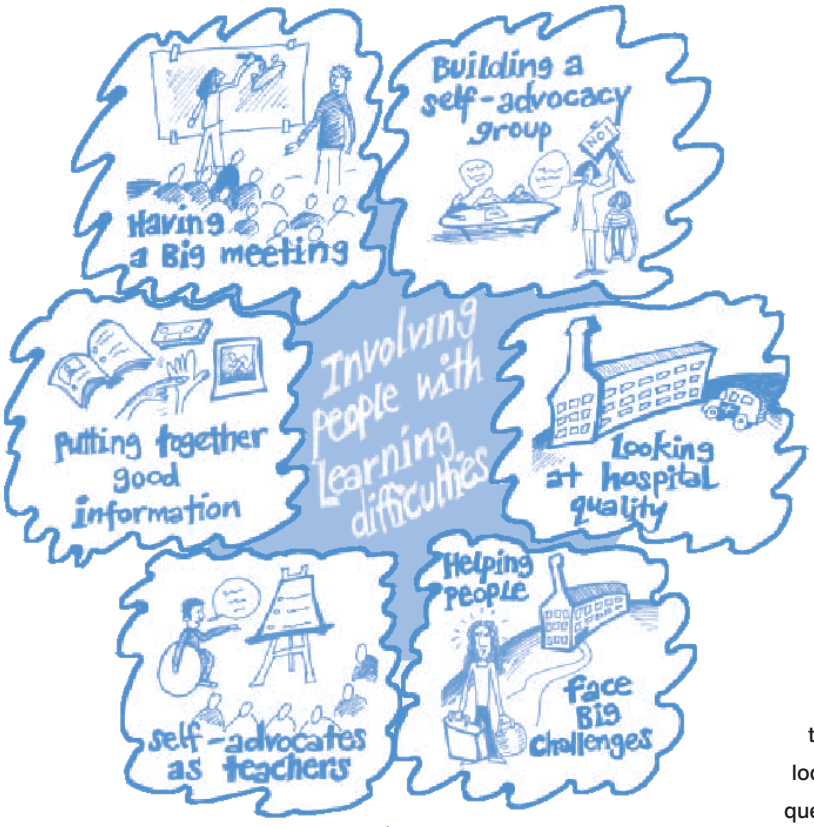


Illustration by Pen Mendonça

Having well-designed opportunities ('interesting and fun') to talk about health issues and be listened to is one starting point for involvement in health issues. County Durham was one of several sites which organised participative conferences to get this dialogue started. Exercise and diet ('watch your waist'); feeling good about yourself ('mind matters'); gender, relationships and health, were all important themes. So were the needs for better information on health issues and what 'health action planning' involves.

Peterborough and Hammersmith and Fulham were two of the sites which took dialogue further by offering support to local self-advocacy groups to pursue their interests in health questions. One role for such groups is as partners in surveys of people with learning disabilities to discover their experience of current (e.g. primary care and dental) services – and as participants with PCT staff in taking action on the findings!

People with learning disabilities are key to producing good information – as well as testing it. In Barnet, relevant staff have worked with self-advocates and family members to produce the 'Hospital Book', recording key information about each individual that they take with them if ever they need to go to hospital. In Peterborough, a similar team has produced an accessible leaflet on 'Going to the Doctor.'

Patient involvement in service audit obviously makes sense, especially true with patients who are more likely to have negative health experiences. As Kirklees has shown, with a focus on hospital access and the way people are treated by staff, involving people with learning disabilities in developing audit questions and supporting them in undertaking systematic checks is becoming a useful tool for improvement in some services.

Personal experience can be a powerful teacher. There are growing examples of people with learning disabilities taking on training roles, for example in raising awareness in general practice and in developing communication skills (e.g. during basic and post-basic professional training). Bracknell Forest pioneered this kind of teaching in primary care, showing also the importance of careful design of the training arrangements so as to maximise staff commitment. Hampshire has been exploring ways of gaining recognised educational accreditation for people taking these training roles. This is also one of the opportunities to pay people for their work!

In every locality there will be some people with learning disabilities facing particular challenges whose involvement in health issues will be especially important. One example is people graduating from special schools. Another is the people still moving out of institutional care. The PCT in Brentwood has made sure that transition planning involves these people directly and helped them, for example, in developing a Health Action Plan and choosing a General Practitioner near their new homes.

speaking up for health

HOW PEOPLE WITH LEARNING DIFFICULTIES CAN HELP PRIMARY CARE TRUSTS DO A GOOD JOB

We all need good health to enjoy a full life.

But on average, people with learning difficulties:

- Have poorer health than other people
- Find it harder to use health services
- Have more bad experiences when they do get treatment.

Primary Care Trusts – the new agencies that lead local health services - are supposed to improve health for all of us.

Over the past 18 months, a team from King's College London has helped PCTs in 12 different parts of England. These PCTs are trying to make sure people with learning difficulties are part of their work to improve health and health services for all of us.

To do this, they have been listening to the experiences of people with learning difficulties and involving them in making things better.

We asked people with learning difficulties, their supporters and local PCT staff in the 12 places to tell us how they have been doing this.

These notes tell their stories. We hope they will help people in other places who want to make sure PCTs do a good job.

summary

Health is important to people with learning difficulties*, like everyone else.

In the new National Health Service, *Primary Care Trusts* have the main local job of making sure everyone gets good health and health services. This includes everyone with a learning difficulty.

We have written a book for Primary Care Trusts (PCTs) about how they can do this. The book is called *Valuing Health For All*.

This *easy to read* section is for people with learning difficulties, their families and advocates who want to get involved in helping PCTs do a good job.

It is written especially for people with learning difficulties and family members in Learning Disability Partnership Boards, self-advocacy groups and others who want to *speak up for health*.

* The people in self-advocacy groups we talked to in writing this pamphlet prefer the words 'people with learning difficulties'. Government papers on health use the words 'people with learning disabilities' instead.

What are Primary Care Trusts?

In every part of England, Primary Care Trusts are the public body with the main job of ensuring that Government plans for the National Health Service are put into action for the benefit of local people.

PCTs in our project included those from some big towns and cities (like Birmingham and Peterborough); London Boroughs (like Barnet); and parts of some big Counties (like South West Hampshire).

The PCTs do their job by:

- Working with the local authorities and other agencies to improve health;
- Using the money from the government to get good hospital and other health services for local people;
- Providing good community health services alongside General Practitioners, for example to ensure everyone gets a good service when they go along to their GP or Health Centre.

All PCTs have a Board which takes the big decisions and which meets in public. They have a local office where the managers work and where you can get more information about their plans and services, including how they are involving the public.

The PCTs (in many areas there is more than one) should have a senior person on the local Learning Disability Partnership Board – the big group set up by the local authority to ensure people with learning difficulties get better lives.

Better Health and Health Services

Self-advocates and their supporters who get involved in helping their local PCT do its job – or look at health alongside other big issues in the Partnership Board – need to make their own decisions about what is important to local people with learning difficulties.

The government says that over the next three years, PCTs must:

- Reduce the differences in health (for example how long we live) between people who are most healthy and others (often including people with learning difficulties) who are not;
- Make it easier, faster and nicer for all of us to get treatment when we need it;
- Improve services, especially on big things like heart disease, cancer, mental health, the help given to older people, children and those who have long term illnesses like epilepsy.

The government also says that people with learning difficulties must be part of all these improvements and get some extra help if they want it through:

- Getting easy to understand information about health questions;
- Making sure everyone is registered with a GP and dentist;
- Having a personal 'Health Action Plan' and someone to help make the plan work (a 'health facilitator');
- Being treated by staff who have the skills (for example in good communication) to take account of their needs.

People with learning difficulties we met put some of this more simply. ***We want:***

- ***To learn how we can stay healthy***
- ***Information we can understand***
- ***Staff who really listen to us.***

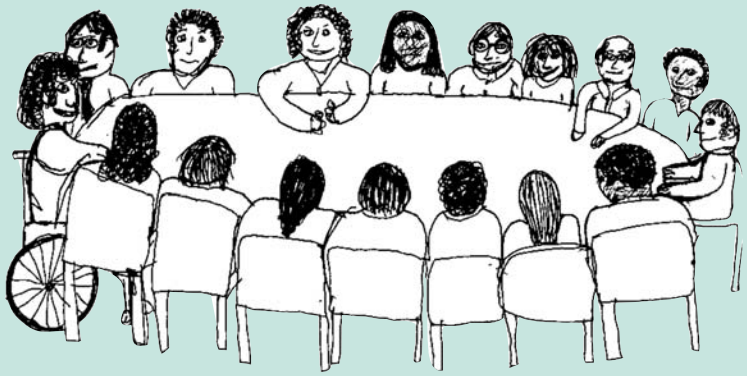
1 Have a big meeting

A good way to start is to find out about what is important to people about their health. What about organising a conference?

In Manchester, this was a day for all the members of Manchester People First, a self-advocacy organisation. There were also staff.

Lots of time was spent in groups talking. To start with men and women talked in separate groups about their health.

In Durham, a conference was planned to be lively, interesting and fun!



There were also lots of different groups on things like:

- **diet and exercise ('Watch your Waist'),**
- **mental health problems ('Mind Matters'), and**
- **dental stuff ('Charming Choppers').**

People from Manchester and Durham told us about some of the main things they were trying to make better. These include:

- Learning more about healthy eating
- Getting better information (for example, about medicines)
- Having a chance to talk about relationships, sex and health
- Getting good support when going into hospital.

Durham people also told us about self-advocates taking part in research to find out more. For example:

- They have done a big survey on what people think about their dentists.
- Their report has been shared with people who answered their questions and the health bosses responsible for good dental services.

getting involved

There are lots of different ways in which people with learning difficulties and their supporters can get involved in helping your local PCT do better.

Here are six examples you might like to think about.

2 Make health a focus for self advocacy groups

Where there are already good self-advocacy groups, they may want to speak up on health issues.

Two groups, one from Peterborough (Peterborough Learning Disability Network), the other from Hammersmith and Fulham (Safety Net People First), told us about some ways they have got involved. For example:

- Having a group to talk about health
- Doing a survey to find out what it is like to use local health services
- Joining in with other people to look at the quality of what the health service provides.

These groups told us some things that would help:

- Good information that is easy to understand about health and health services
- Doctors, dentists and nurses taking time to listen and explain things properly
- Support from someone you choose, to help you think about your health and use health services.

3 Put together good information

People with learning difficulties need good information.
Staff who work with people with learning difficulties need to be good at supporting them on health questions.

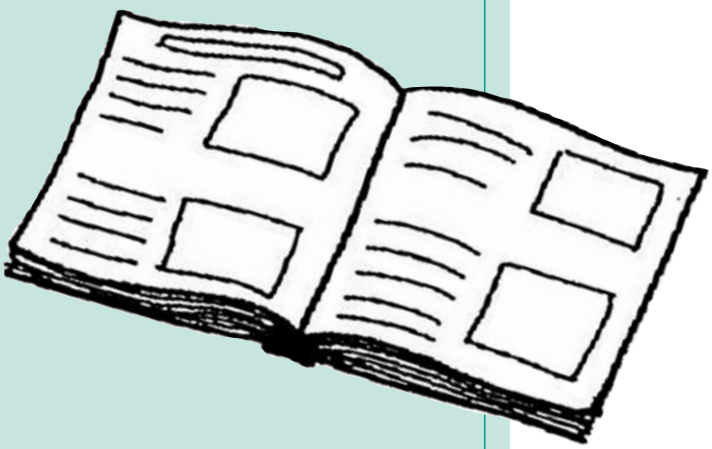
In Barnet, the PCT has encouraged hospital and community nursing staff to work with people with learning difficulties and carers to write a 'Hospital Book'. This is a record of key information about the person - which they can take with them if they ever need to go to hospital.

A group also wrote a guide to good practice in supporting people when they go to hospitals.

In the local hospital, there are 'link staff' on each ward who know about how to help.

People with learning difficulties train these staff on the importance of communication.

Now someone with a learning difficulty is also meeting people living in residential care to teach them about the 'Hospital Book' and train staff in how it is used.



4 Look at hospital quality

A group from Kirklees told us about how they are trying to improve Dewsbury Hospital.

Some managers there know that people with learning difficulties face problems in acute hospitals. They have encouraged self-advocates to help them make improvements.

The self-advocates have been doing an audit – checking off how good the hospital is on a list of things which make access easier. This list covers:

- Finding your way around the hospital
- The help you get, for example from reception staff
- The ways doctors and other staff treat people with learning difficulties.

To begin with, this checklist just had things to be ticked. Now it has been improved so that the questions all have pictures and there is room to write comments.

The self-advocates also take photos to show staff what they found.

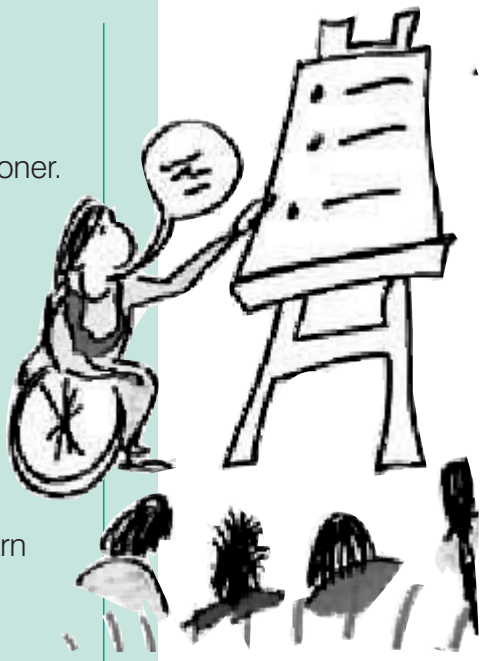
All this is told to a hospital staff group who are responsible for making improvements.

Another group is looking at how people with learning difficulties get on when they visit general practitioners, dentists and opticians.

With thanks to Pen Mendonça for illustrations used in the Speaking Up For Health chapter, and:

Pictures from People FIRST 020 7485 6660

5 Self-advocates as teachers



In many places, Primary Care Trusts are working hard to ensure everyone with a learning difficulty is on the list of a General Practitioner.

It is important that GPs and surgery staff understand people with learning difficulties and are good at meeting their needs.

In Bracknell, self-advocates have been playing an important part in training GPs and staff.

The Bracknell group told us:

- It is important that training is about things staff are keen to learn
- Training should be arranged (for example over lunch-time) to fit in with the work of staff
- The best kind of teaching is where staff listen to people with learning difficulties talking about their experiences
- Self-advocates need support to learn how to be good teachers.

It will take quite a long time to do this kind of training in every General Practice. But by improving understanding, it can lead to good ideas which are useful everywhere, for example:

- Staff giving longer appointment times for some people who need this
- Practices starting to make use of a 'Personal Health Record' for each patient who wants this.

At the same time:

- People with learning difficulties are getting better at speaking up for themselves.

We also heard about a Medical School (St. George's, in London) which employs people with learning difficulties to teach medical students. These students learn about good communication right from the start of their training.

further information

A good general guide to getting involved in making things happen is *Getting Control of My Life* available from King's College London, Centrevents (Tel. 0207 848 3740).

It is important that people from minority groups, for example Black and Asian people with learning difficulties, are included. Some of the reasons for this are set out in *Learning Difficulties and Ethnicity: Summary Version* free from the Department of Health, PO Box 777, London SE1 6XH.

Greenwich PCT, in consultation with Working with Words, has put together a big list of material about health for people with learning difficulties. Contact Stephen Whitmore at Greenwich Primary Care Trust Tel 0208 836 4638.

This includes a series of *Books beyond words* about keeping healthy, available from Book Sales at the Royal College of Psychiatrists Tel 0207 235 2351.

The Department of Health has produced accessible guides (both written and on tape) to Health Action Plans *Health Action Plans. What are they? How do you get one?* Available at the PO Box 777 address above. (Also Fax 01623 724524).

One example of a *Personal Health Information File* has been produced by North Somerset PCT. One example, from County Durham, of people with learning difficulties undertaking a survey of health services is *Our Dentists…a report by service users on their Dental Services*. These and the Barnet PCT *Hospital Book* are available from the BILD library Tel 01562 723014.

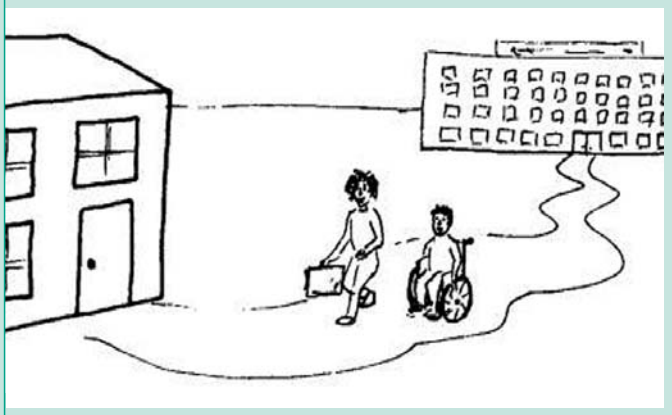
6 Help people face big challenges

Some groups of people may need extra help. We heard about the example of people moving out from living in learning disability hospitals.

People who used to live in Little High Wood Hospital told us about moving to new homes in Brentwood.

They said it was important:

- To get involved in planning the move
- To find people to support you the way you want
- To choose a doctor who you can visit from your new home
- To have a health checklist.



Next Steps

These are just some of the ways people with learning difficulties can help the local Primary Care Trust do a good job. People reading and discussing this pamphlet will probably come up with lots of other ideas.

We hope you will tell your PCT what you think. If you don't know who best to talk to, ask the Chief Executive.

We have included this pamphlet in Valuing Health For All so that PCT staff who read our book can use it as one way of talking to people with learning difficulties and their supporters about what they think is important in improving health and health services.

We expect you will also want to talk about how the PCTs are getting on in the Learning Disability Partnership Board meetings.

the health for all agenda

Addressing the Health For All Agenda in Mainstream Services

Here we consider in turn the PCT responsibilities for health and mainstream health services, and how the health of people with learning disabilities may be positively included.

REDUCING HEALTH INEQUALITIES

The Government made clear in its strategy on health inequalities (November 2002) that it is determined to tackle serious health inequalities. People with learning disabilities were explicitly acknowledged as one group for whom targeted intervention is appropriate. The aim of the strategy is:

- To narrow the gap in health outcomes across geographical areas, across socio-economic groups, between men and women, across different black and minority ethnic groups, age groups, and between the majority of the population and vulnerable groups and those with special needs.

Health inequalities relate to economic, environmental and other quality of life issues as well as the functioning of local health services. Great emphasis is placed on ensuring that action to reduce health inequalities is built into a range of priority programmes, including through specific targets. Local Public Service Agreements are key vehicles for making real progress at local level, involving financial rewards for meeting "stretch" targets – particular focus is given to infant mortality and life expectancy. It is clear that the approach has to involve agencies and services other than the NHS and that progress will be made through working in partnerships that, importantly, include people who use services.

Health inequalities faced by people with learning disabilities

The Valuing People Support Team paper ***Improvement, Expansion and Reform – ensuring that "all" means "all"*** encourages PCTs to consider how their key national priorities (as contained in the 2003-2006 Planning and Performance Framework) can be furthered by paying particular attention to the needs of people with learning disabilities. The paper also summarises evidence about the health inequalities experienced by people with learning disabilities – in terms of both their health and their access to health services.

Key aspects to bear in mind here are:

- The majority of people with learning disabilities live on Social Security benefits.
- The available evidence clearly shows that people with learning disabilities have poorer health and receive poorer support (than the general population) from the NHS across a range of health issues, including cancer and coronary heart disease.

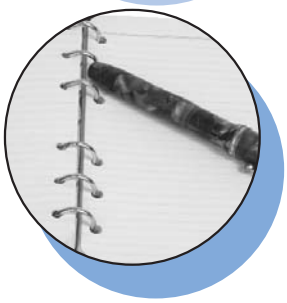
summary

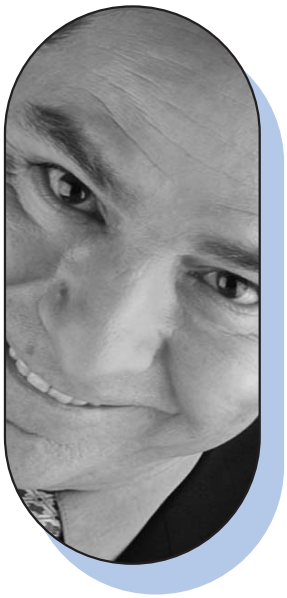
People with learning disabilities often have poor health. They may get worse help from health services than most other people. The Government wants everybody to have the same chance of a healthy life. This is the job of the local NHS and others working in partnership.

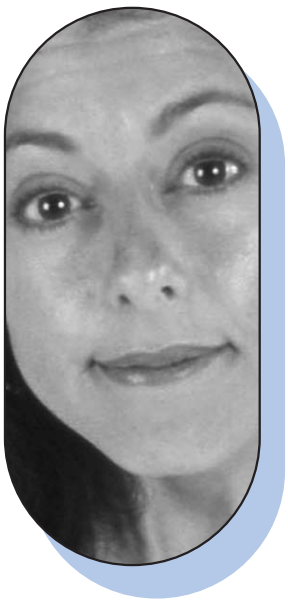
PCTs have targets for improving services for everyone (for example, for cancer and heart disease). Including the health needs of people with learning disabilities may help PCTs meet their targets. Knowing about the health needs of local people is a key starting point for PCTs.

GPs and other health professionals in primary care should work together to identify the health needs of people with learning disabilities. They should help people to get the right services.

Primary health services and hospital services can be improved by listening to the experiences of people with learning disabilities and acting on the results. Information and training can help with this.







the health for all agenda

- Both the cancer and CHD objectives are explicitly to reduce inequalities. They state that all patients should have access to prompt, high quality services for prevention, diagnosis, treatment and care.
- The 'Reducing Health Inequalities' objective requires the NHS to ensure that 'distribution of health benefit… consistently favours individuals and communities that have been traditionally under-served'.

Addressing the health inequalities of people with learning disabilities should follow the same basic pattern as for other people:

- Obtain a good awareness of health conditions, including environmental as well as personal health
- Engage with those people who are directly concerned
- Be clear what is needed to improve these conditions
- Ensure that there is good access to the appropriate services
- Have the evidence about what interventions work best and ensure that these are provided effectively.

Project experience

Health inequality targets (such as increasing life expectancy) are influenced by a number of factors; demonstrating an effect can be difficult in the short term. Local information on the health status of people with learning disabilities was not sufficiently sensitive at either population or individual levels.

The development of accurate information on the health needs of local people is therefore an essential starting point. Such data can perform many functions, such as:

- Raising awareness of the poor health status of people with learning disabilities and the consequent need for PCTs to focus attention on them
- Identifying specific health issues that might be candidates for local initiatives
- Providing the basis for target setting and monitoring.

For example, the leading recorded cause of death for people with learning disabilities is respiratory disease. Yet people may not know about or request influenza immunisation. All the localities in the project identified development of effective information systems as a challenge.

Action towards addressing health inequalities took various forms:

- Raising awareness of PCTs and practices about health and access issues for people with learning disabilities
- Supporting people with learning disabilities to learn more about health and health services
- Ensuring that people with learning disabilities were registered with a GP
- Making practices aware of patients registered with them who might need specific consideration arising from their learning disability

- Introducing health checks (as a foundation for health action planning) and recording the results on practice information systems
- Including a learning disability perspective in NSF and Cancer Plan implementation groups
- Surveying access to primary care and hospitals and acting on the results.

A theme in many sites was that people outside the NHS do not see good health as their responsibility. NHS staff may undertake the vast majority of health interventions, but others have a responsibility for ensuring that those skills and services are obtained when needed and for understanding the broader components of health inequalities.

The project sites were driven by a clear intent to address inequalities. As individual initiatives progressed, the sites began to see that an overall strategy for the health of people with learning disabilities should be linked to other strategies that address poverty and disadvantage, including those that deal with the NHS Plan, the modernisation of local government, neighbourhood renewal and housing. The relationship of the Learning Disability Partnership Boards with Local Strategic Plans will be an important factor in making progress here.

EXAMPLE

Manchester's People First group held a Health Promotion day. They invited a number of professionals, such as a practice nurse, a health visitor, a PALS officer and a sexual health worker to come and talk about their jobs. Each discussed with people with learning disabilities how they could provide them with a service that was more accessible and more inclusive. Four people with learning disabilities shared their personal concerns about health issues. They had designed their own posters about the issues they wanted to talk about:

- **sexual health and relationships**
- **substance misuse (alcohol, smoking, drugs and health problems)**
- **hospital admissions**
- **healthy eating.**

Manchester People First produced a booklet, 'Our Health Matters', which gives information on these topics and more, in their own words and with pictures (obtainable from People First, Manchester).

EXAMPLE

Many practices believe that they can identify their patients and therefore their needs, but people with learning disabilities may not be registered with a GP or may not have been to their GP regularly, or for some time. Their needs will not be fully understood or met. In Peterborough and Brentwood people with learning disability from long stay health institutions are now registered with a GP practice for the first time. Practices in some areas set up registers on their computer systems with the basic patient details. Others introduced a 'health check' system - a baseline assessment with the GP and/or practice nurse. The practice may be supported in this by members of the community learning disability team (e.g. a specialist nurse). This information can then be recorded on the practice information system and used at an individual level to obtain services for the patient or at a PCT level for audit and planning purposes.

Peterborough, Bracknell and Hammersmith & Fulham introduced health checks based on locally developed processes and protocols. The 'OK Health Check' used in Durham & Darlington is another recognised method of recording health status. The introduction of health checks ensures that everyone with a learning disability is registered with a GP and can lead on to Health Action Plans, as required by *Valuing People*.

BETTER SERVICES AND OUTCOMES

Cancer

The incidence of cancers amongst people with learning disabilities is increasing rapidly, but diagnosis and treatment may be delayed due to problems of access to both primary and secondary health care. For example, women with learning disabilities are much less likely than other women to participate in breast and cervical screening. It is therefore important that the local cancer network gives specific consideration to the needs of people with learning disabilities as they work on their local plans for improving prevention, treatment and palliative care. For example, anti-smoking initiatives should include and be accessible to people with learning disabilities. Addressing problems in access to screening will help practices and PCTs to improve their performance against targets; experience in one project site showed that user-friendly information developed for women with learning disabilities was welcomed by other women. Several other sites worked to ensure that cervical and breast screening were easily accessible; in Manchester the local Cancer Plan group was moving on to include people with learning disabilities in other cancer service improvement plans. Kirklees' palliative care network focused on accessible information and shared training to improve access.

Heart disease

Almost half of all people with Down's syndrome are affected by congenital heart problems. Coronary heart disease (CHD) is the second most common cause of death in people with learning disabilities and rates of CHD are increasing in this population. Risk factors such as weight problems, poor diet and low levels of physical activity are common. Again, health promotion advice should be provided in accessible forms. Practice based registers can be used to identify people with learning disabilities who might be at high risk of CHD.

EXAMPLES **In Manchester a PCT contributed funding to support a local 'fighting fit' campaign. Development of care pathways for relevant conditions (hypertension, obesity, diabetes) is including special consideration of how to include people with learning disabilities.**

Use of the appropriate clinical coding systems will enable cancer and CHD services performance to be monitored in relation to people with learning disabilities.

Mental health

Prevalence of schizophrenia is about three times higher in people with learning disabilities and reported prevalence of anxiety and depression is similar to that in the population as a whole; a very high proportion of people with learning disabilities are being prescribed psychotropic medication. There is a long history in many areas of 'boundary disputes' between mental health and learning disability services. Project sites made efforts to address mental health issues through NSF implementation groups, but this was not successful everywhere. However, North Somerset had strong links between learning disability and mental health services and Durham & Darlington were exploring a primary care link worker model to improve identification and early intervention. A separate national project is developing good practice advice and materials to improve links between mental health Local Implementation Teams and learning disability Partnership Boards.

IMPROVING THE OVERALL EXPERIENCE

All NHS organisations have a legal responsibility to provide equality of access to health care, which includes people with learning disabilities. The Disability Discrimination Act requires organisations to make 'reasonable adjustments' to ensure that people with disabilities are not excluded from services and do not get worse services. The experiences of people with learning disabilities from the project sites bore out national reports of problems that people with learning disabilities may encounter with access to health services. These may be to do with:

- Physical access (e.g. lack of wheelchair access)
- Attitudes (talking to a carer instead of the person, shouting)
- Information and communication (complicated language, small print, confusing signage)
- Processes (inflexible appointment systems, long waits).

People with learning disabilities from minority ethnic communities may experience additional problems of racism and lack of awareness of cultural needs. For example, some women may need to see female health professionals and may avoid services if this cannot be guaranteed. In Birmingham the project found that some people with learning disabilities from Muslim families found it very difficult to see a GP if their mothers could not go out unaccompanied and home visits were not offered. Identifying the problem for people with learning disabilities may encourage PCTs to address such issues for everyone.

further information

Health and Neighbourhood Renewal: guidance from the Department of Health and the Neighbourhood Renewal Unit (2002). **www.doh.gov.uk/healthinequalities**

Community strategies and health improvement: a review of policy and practice (2002). Health Development Agency. **www.hda-online.org.uk**

National Service Frameworks: a practical aid to implementation in primary care (2002). Department of Health. **www.doh.gov.uk/pricare/nsf.htm**

Improvement, expansion and reform: ensuring that 'all' means 'all' (2003). **www.doh.gov.uk/vpst**

Signposts for success in commissioning and providing health services for people with learning disabilities (1998) and *Once a Day* (1999). Department of Health.

Include Us Too: developing and improving services to meet the mental health needs of people with learning disabilities (2002). Cole, A. Institute for Applied Health & Social Policy, King's College London. Tel **020 7848 3770**

EXAMPLES

Self advocates in Hammersmith & Fulham did a survey of access to primary care and produced some suggestions for doctors, dentists and receptionists. Some of these were about attitudes ("Don't just talk – let us talk too – and please listen!") and some were recommendations for 'reasonable adjustments' such as offering double appointments or a first or last appointment. Durham & Darlington self advocates surveyed access to dentists.

Bracknell organised awareness training for whole primary health care teams, with people with learning disabilities as co-trainers. This allowed teams to hear firsthand about access problems and provided opportunities to solve problems together and explore issues of common concern, such as communication. The initiative is being developed to tackle access for people with profound and multiple disabilities.

Hospital services

Hospital care can seem daunting to any patient, but vulnerable groups such as people with a learning disability can find it very frightening. Several sites worked on access to hospital services. For example, self advocates in Kirklees agreed with hospital managers to visit and audit:

- Finding your way around
- Help from reception staff
- Staff attitudes

The results are being used by the hospital to make improvements that will benefit everyone.

Family carers, self advocates and health staff collaborated in Barnet to produce a 'hospital book' – a record for each person of important information that they can take with them to hospital. This includes information about how the person communicates, and indications of any support that is important for their health and safety. A 'link nurse' on every ward was trained to ensure that someone with a learning disability would be well supported during their admission. In Manchester hospital staff induction and customer care training now includes information about people with learning disabilities.

Modern matrons, Patients' Forums and PALS may help address these issues in the future. Manchester agreed with the PALS officer at South Manchester University Hospital to always include a person with a learning disability in any discussions on policies, guidelines, patient information or any changes to existing facilities or new facilities.

specialist contributions

Reshaping Specialist Contributions from Community Learning Disability Teams

A LITTLE HISTORY

In the past, people with learning disabilities have often not had their general health needs well looked after by mainstream health services, despite evidence on the poor health experienced by many. In order to try and meet needs, some Community Learning Disability Teams (CLDTs) provided in effect a 'parallel' health service. There have been some unfortunate consequences of these well-intentioned efforts:

- People with learning disabilities are often not well served by primary, secondary or tertiary mainstream NHS services; sometimes this is because they have been 'diverted' to specialist services and are regarded as the responsibility of those services. Yet interventions from these specialist services are often focused on a sub-set of the population; the rest may have little contact with health services and many suffer for years with undiagnosed or inadequately treated health problems.

- Some disabled children have been 'diverted' at a very early age to a specialist paediatric service for all their health needs, never even being registered with a GP. Around the age of 19 they are transferred to adult services and expected to use primary care services: at a vulnerable age this can be a very difficult introduction to generic health services.

- These 'parallel' approaches have isolated people with learning disabilities from the help they need from mainstream health professionals and from inclusion in mainstream priorities and funding. It has also prevented mainstream health professionals from acquiring the skills they need to support people with learning disabilities (particularly skills in communication).

- Learning disability health professionals have also often been isolated professionally: sometimes regarded as marginal both by mainstream health services and by social care staff who have not always appreciated the importance of health.

summary

People with learning disabilities have often not been able to use the same health services as everybody else. Specialist learning disability health professionals need to work differently to change this. They need to balance:

- **continuing special help for individuals who need it most**

- **helping people with learning disabilities, family carers and supporters to know more about health and health services**

- **working with ordinary health services to help them do their jobs better.**

specialist contributions

DEVELOPING A NEW BALANCE

Learning Disability Partnership Boards are required to review CLDTs to ensure that specialist professionals are working together and with partners to deliver the aims of ***Valuing People***. A theme running throughout ***Valuing People*** is that people with learning disabilities should be better served by 'mainstream' services – those used by everybody. This includes health services, as poor health can be a significant barrier to taking up better opportunities in life. The White Paper required the development of a new role – health facilitation, to promote health and access to health services – and a new focus on health action for individuals – Health Action Plans, linked to person centred plans.

Amongst other things, review of CLDTs must therefore include review of how specialist health professionals use their skills and balance the various roles now demanded of them. In addition to their specialist clinical and therapeutic roles, they have a duty to facilitate and support mainstream health professionals to provide better quality services to people with learning disabilities. ***Valuing People*** and the subsequent guidance expects them to develop:

- Health promotion roles, working with health promotion colleagues
- Health facilitation:
  - with individuals to help them think about their health and get the services they need via Health Action Plans
  - development work to address health inequalities and help mainstream health services to develop the skills required to meet the health needs of people with learning disabilities
- Teaching roles, including ensuring that everyone who supports people with learning disabilities becomes more aware of health issues and how to gain access to appropriate services
- Service development roles, contributing their expertise to planning processes.

Achieving such a balance is likely to require some refocusing of time and energy from individual interventions, whilst maintaining the provision of additional specialist services for those who need them most – likely to be people with complex needs. People should of course still be supported to use mainstream health services to whatever extent is appropriate individually.

BUILDING NEW RELATIONSHIPS

In many areas learning disability health professionals have worked most closely with others in the learning disability 'world'. The new roles require them to develop or strengthen relationships in the NHS 'world' – with mainstream practitioners, support staff, professional leaders and managers in PCTs and NHS Trusts. Learning disability specialists need to be thoroughly familiar with mainstream priorities and processes so that they can promote the inclusion of people with learning disabilities. This will include helping people with learning disabilities and their families to understand and engage directly with NHS organisations. Specialist professionals can also show that the inclusion of people with learning disabilities will benefit the wider development of local health services.

EXAMPLE **CLDT reviews in project sites explicitly acknowledged the need for specialist health professionals to 'face both ways' between the learning disability and NHS worlds. Learning disability professionals supported self advocates in most sites to discuss health issues and begin to engage with mainstream services – as advisers and trainers (e.g. in Manchester and Bracknell) as well as being service users. Initiatives to improve access for people with learning disabilities (e.g. the hospital in Kirklees and screening in Barnet) resulted in improvements for other groups also, such as people with poor vision and those for whom English is not their first language.**

SHAPING THE SPECIALIST CONTRIBUTIONS

Health promotion

It is clear that people in different organisations must work together to promote good health. Some of the major health problems, such as obesity, must be tackled by all who contribute to the care and support of an individual. Many people with learning disabilities have not had the opportunity to learn about healthy living and a healthy lifestyle. Sometimes this has been due to lack of accessible information. Person centred planning and approaches have occasionally been misinterpreted as excluding health and meaning that poor lifestyle choices on the part of someone with a learning disability must be accepted. Health promotion must include the opportunity to understand the consequences of lifestyle choices. Specialist professionals can educate and support family carers, support workers and other health care staff. Their contribution may include:

- Ensuring that specific health risks associated with a particular learning disability syndrome are known about by families, support staff and primary care teams. People with Down's Syndrome, for example, have a higher than average risk of heart disease, thyroid problems and, as they get older, Alzheimer's disease
- Supporting health promotion professionals to make their information and campaigns accessible and inclusive
- Supporting self advocacy groups to explore health issues and connect with local health services.

EXAMPLES **Birmingham produced a list of the most common syndromes and associated health risks for the GP and practice nurse who were carrying out health checks.**

Durham & Darlington and Manchester held events on health for people with learning disabilities, their families and carers. These were designed to be fun; they included groups talking about different health topics and stalls with information on different services and aspects of health care.

specialist contributions

Health facilitation

The guidance on developing health facilitation and Health Action Plans states that facilitation at the individual level – focusing on improving the health of one person at a time – is a role that may be fulfilled by a variety of people, including family members and support workers. However, it is expected that health professionals will make important contributions to individual plans – helping to identify, meet and monitor health needs and arrange access to the right services. People with learning disabilities who have complex health needs may want a specialist professional as their facilitator – for example, a learning disability nurse or therapist. A further new role for some specialist professionals may be supporting the introduction of Health Action Plans – supporting other people to become facilitators and working with primary health care teams to help them get involved. In a number of project sites, learning disability staff have worked in this way to get health checks under way, to act as a basis for Health Action Plans.

EXAMPLE **In Hammersmith and Fulham a learning disability nurse and a primary care nurse consultant collaborated to develop a local approach to health checks. West Hampshire NHS Trust developed a resource pack for health professionals on common health problems associated with learning disability.**

Health facilitation at the service development level is exemplified in the way learning disability professionals have taken on new roles to tackle health inequalities. An initiative from one of the project sites was quoted in the national guidance – Birmingham appointed a project nurse and GP adviser to support practices to identify their patients with learning disabilities and update practice information systems with the appropriate Read code. Further examples include:

EXAMPLES **A protocol for planned hospital admissions and discharges: Manchester's project worker involved three CLDTs, Manchester People First and the South Manchester University Hospitals Trust in agreeing good practice guidelines for staff who are treating and looking after people with learning disabilities in hospital. Where appropriate, a 'care co-ordinator' from the CLDT will be appointed to make sure that hospital staff give proper support to the person with learning disabilities and keep contact with family and carers to ensure that the whole process is a high quality and positive experience.**

A protocol for school leavers: the Manchester CLDTs ensure that the CLDT, the young person and their family/carer, Connexions, the school nurse, Disability Rights advisers, Children's Teams and the Manchester Learning Disability Partnership all get together to help the young person to make important decisions about what will happen when s/he leaves school.

Kirklees CLDT are involved in a project to enable people with learning disabilities who have terminal cancer to access hospice care. They are also involved with hospice staff, offering training and support to enable them to meet the needs of people with learning disabilities.

Teaching

Teaching roles may involve underpinning the general health knowledge of others with specialist knowledge and understanding, or supplementing knowledge of learning disability with expertise in health and health services. For example, learning disability professionals from the project sites became involved in:

- Teaching fifth year medical students (York)
- Giving awareness training to primary health care teams and using 'protected learning time' sessions to address issues such as consent to treatment
- Supporting self advocates to become co-trainers
- Ensuring that support contracts for people moving out of a long stay hospital included attention to health (Brentwood).

Service development

Key planning and development forums in PCTs include the Professional Executive Committee and the commissioning or planning group. Learning disability staff (practitioners and managers) can make important contributions in these groups and with hospital forums such as PALS. The preparatory work on health checks and information systems done in a number of project sites will yield better data in future about the health status of people with learning disabilities; this will help to ensure that health inequalities are identified and addressed. It is also crucial to have robust representation of health issues on the Learning Disability Partnership Board, so that health issues are not unintentionally overlooked amongst all the other priorities for development.

further information

Review of the role and function of Community Learning Disability Teams: review toolkit (2002). Valuing People Support Team. **www.doh.gov.uk/vpst**

Action for health - Health Action Plans and Health Facilitation. Detailed good practice guidance on implementation for Learning Disability Partnership Boards (2002). **www.doh.gov.uk/learningdisabilities/healthactionplans.htm**

UK primary health care network (relating to the health of people with learning disabilities). Contact Janet Cobb – **janet.cobb@nwtdt.com**

Acute care network (relating to the health of people with learning disabilities). Contact Rick Robson – **rick.robson@shrop-comm.wmids.nhs.uk**

checklist

What the PCT can do

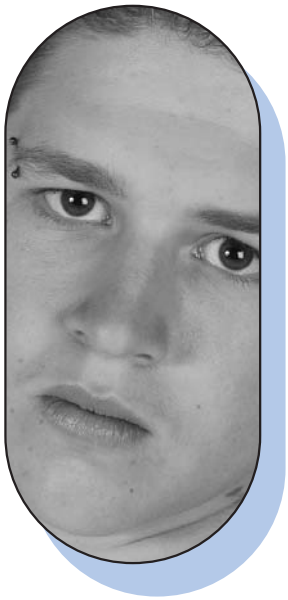
- Nominate a 'lead' person with sufficient seniority to ensure that the health of people with learning disabilities is included in PCT priorities and Local Delivery Plans; that the health dimension is included in the commissioning of learning disability services, and that the PCT is well represented in the Learning Disability Partnership Board.
- Use ***Improvement, expansion and reform: ensuring that 'all' means 'all'*** to select appropriate targets. Encourage learning disability specialists to contribute to the implementation of NSFs, Cancer Plan, etc.
- Address the health inequalities experienced by people with learning disabilities through health improvement plans (e.g. via Local Strategic Partnerships) and equity audits
- Identify a senior practitioner (probably a GP or nurse) who can act as a 'champion' in professional forums such as the PEC and the clinical governance committee. Their role could include identifying any concerns of practitioners about working with people with learning disabilities
- Make sure that people with learning disabilities are registered with GPs and dentists. Support provision of a variety of health information in accessible forms
- Check that the development of information systems (such as practice registers) includes appropriate coding of learning disability (Read code E3), so that better data on health and access may be collected for future use
- Invite people with learning disabilities to make a presentation to the PCT Board about health and access to health services, perhaps to introduce the topics of Health Action Plans and health facilitation. Draw on the expertise of specialist learning disability services to support these initiatives
- Include people with learning disabilities and family carers (including people from black and minority ethnic communities) in surveys and other means of listening to patient and public views (e.g. PALS, Patient Forums). You could commission a local self advocacy group to conduct service audits
- Make sure that training and development plans support both 'awareness raising' and 'in depth' training on specific appropriate topics (you could involve self advocates as co-trainers)

What primary health care teams and secondary health services can do

- Ask one person in the practice or service to take a special interest and make sure that the health of people with learning disabilities is included in (not additional to) your main priorities
- Invite representatives of the community learning disability team to a practice meeting or clinical governance forum to discuss:
  - the health needs of people with learning disabilities who are registered with the practice or use your services
  - any concerns you have about working with people with learning disabilities (for example: consent; communication; people arriving at the surgery or hospital without proper information)
  - how the specialists can support you to do your job (for example, helping you to include people with learning disabilities in your access and screening targets)
- Collaborate with the PCT and specialist services to introduce Health Action Plans
- Ensure that practice and hospital information systems capture information on the health of people with learning disabilities, combining clinical data (such as risk of heart disease) with Read code E3 (learning disability)
- Use the data to audit health risks and access to appropriate interventions (for example as part of action on National Service Frameworks)
- Involve people with learning disabilities and family carers in practice or service audits and Patient Forums
- Include learning disability awareness in your training plans. Invite people with learning disabilities to talk about their experiences

What learning disability services can do

- Make it a priority to learn about the mainstream NHS priorities, targets and funding; seek out the links with the health and access concerns of people with learning disabilities. (Use ***Improvement, expansion and reform: ensuring that 'all' means 'all'*** to help you make the connections)
- Collect information about the health status and health risks of people with learning disabilities and use it to raise awareness in PCTs and mainstream health services about key health and access issues for the population
- Go to the PCT forums where clinical priorities are discussed and decisions made (for example, National Service Framework groups, clinical governance meetings, care pathway groups). Show how including people with learning disabilities can help deliver their priorities (e.g. meeting targets for cancer screening). Offer your skills to contribute to corporate objectives too
- Support people with learning disabilities to become better informed about health, to register with GPs and dentists, to know how to use health services, to get active on issues such as access, and to get involved with the PCT, e.g. via Patient Forums



checklist

- Similarly, support all services to understand and accept their responsibility for promoting good health for all
- Work with PCT training organisers to develop and offer a variety of locally relevant training. Make sure you are clear that you want to help mainstream services to do their jobs better, not to become experts on learning disability
- Collaborate with PCTs and primary health care teams to introduce Health Action Plans and health facilitation
- Help practices and other health services to identify patients who may need specific consideration arising from their learning disability
- Support review of the role and function of community learning disability teams to ensure a locally appropriate balance between specialist individual interventions and the range of activities suggested above

What people with learning disabilities and their families can do

- Find out how health services are organised in your area. Find out how the needs of people with learning disabilities and their families are included in the priorities of PCTs and other organisations. Find out the different ways you can get your views across
- Make sure you are registered with a GP and dentist of your choice
- Get involved in events for people with learning disabilities about staying healthy. Find a chance to discuss things that are important to you. Invite some health professionals to talk about what they do and how they can help
- Put health issues on the agenda for your local self-advocacy or 'speaking up' groups
- Let the PCT and other health services know what you think is working well and what you think needs to be improved. Help the NHS identify which groups of people and what kinds of health issues need to be given more attention
- Find out about good sources of information about health. Share with others what you find useful. Help to produce good information about local health services and what people should expect
- Get involved in deciding how Health Action Plans will work locally. Join with others (e.g. people involved in the Learning Disability Partnership Boards) in reviewing progress
- Offer to do surveys and checks to find out what health services are like for people with learning disabilities to use
- Help the Patient Advice and Liaison Services get good at helping people with learning disabilities (including finding independent health advocates when required)
- Get involved in training health professionals and service teams.

learning together

To return to our starting point, this has been an account of lessons from the experience of 12 project sites PCTs and their partners' in different parts of Britain in the first year or more of their efforts to engage with a large local agenda for improving health and health services. They are all still travelling hopefully!

Not surprisingly, starting from different situations and challenges in achieving ***Health For All***, different places made different progress on different issues. In relation to people with learning disabilities, progress was most solid where local 'champions' were skilful in ensuring their needs were included in work on mainstream health priorities, including NSF implementation, and gained momentum where this agenda also formed part of other key activities, for example concerned with clinical governance and the development of PALS. In turn, these efforts were further reinforced and made more responsive where people with learning disabilities and their supporters got directly involved in shaping the agenda and helping to deliver some of the activities. And all this was more likely and more productive where specialist learning disability staff were able to reshape their contributions so as to bridge the learning from these services and the development of mainstream inclusion.

The preceding **Action Checklist** highlights some of the most productive of these different contributions and the need to make connections among them to deliver sustainable change, not just for the few but for the many.

What we are seeing at best is the gradual emergence of a positive spiral of development, starting with particular initiatives addressed to relevant mainstream priorities and people perhaps most at risk, building in new ways of working which benefit a wider set of people and then learning from this experience in the next round of the cycle as suggested in the diagram on the following page.

afterword

It is still early days in the development of PCTs as the local champions for health: there is even more to do to ensure that traditionally excluded groups of the population like people with learning disabilities are part of the *all* in current strategies for improving health and health services. Wider progress is most likely where:

- **Local interests work together to build momentum for positive change;**
- **Promising early initiatives become the starting points for a continuing cycle of development;**
- **There is local investment in learning from experience so as to inform wider change.**

This **Action Guide** is designed to offer one stimulus to this wider learning.

cycle elements

LEARN

LISTENING TO PEOPLE

BUILDING ALLIANCES

PLAN

ASSESSING PERFORMANCE

BUILDING VISIONS

HOW PCTs CAN HELP

DELIVER

IMPROVED CAPACITY

SMALL AND LARGE ACTION

PROGRESS REVIEW

Achieving Positive Change!

ELEMENTS IN THE CYCLE OF DEVELOPMENT

In conclusion, we believe this positive cycle is most productive where the different interests to whom this **Guide** is directed make the commitment to learn together from local experience. We hope that reflection on the lessons we have drawn from the sites in the national project offer a valuable stimulus to learning together elsewhere.