

# Affecting change locally – how family carers can have their voices heard



Learning disabilities and family carers project 'How-to' guide 1

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## 1. This guide

**Suggested action points in this guide are in bold.**

This guide is the first in a series of three 'How-to' guides for Crossroads Care providers and The Princess Royal Trust for Carers' Centres supporting family carers of people with learning disabilities as well as, increasingly, giving people with learning disabilities a break from their caring role.

Many people with a learning disability live at home with parents or other family carers who are getting older and who need increasing support and care themselves. Others leave home to marry or live with a partner or friend who might need extra help and support because of their disability. Their needs might be very different from someone with a learning disability who is cared for by their family. Everyone's voices need to be heard in the local planning structures.

## 2. Learning disability services

Services for people with learning disabilities don't, of course, just happen. There is a mix of provision from local health services and local

authorities who also pay other organisations to provide services. Services come under one of three different levels of authority:

- Where authorities are told to provide some things by law.
- Where they are expected to provide some other services by government. These don't legally have to be provided; details are usually given in guidance to authorities and have varying levels of enforcement and checking. Authorities may be looked upon dimly by the responsible inspection bodies that will be marking on such provision if they are not provided.
- Finally there are some things authorities might choose to do, for the benefit of their local communities for instance.

Many of the services that people with learning disabilities use are, of course, now generic. There is a greater expectation that people with learning disabilities should be using the same mainstream services that everyone else uses. There is also an increase in the inclusion of people with learning disabilities in general disability groups and activity. There are, therefore, three areas that are included in this guide, learning disability services, disability services generally and generic mainstream services.

There has always been a difference in exactly how local authorities do their work and what services they provide. This is still very apparent; for example, some authorities spend 12% of their budget on residential care for people with learning disabilities whilst others spend 80%. As guidance has tried to move us towards more independent living one can see the varied effect this has had in different parts of the country. Sadly, those with the higher spend “achieve worse results”.<sup>1</sup>

Additionally, there has been an increase in local decision making powers as government has tried to be seen as less controlling. Here it may often be useful to be aware of what is happening in other areas and how closely an authority is following guidance or not. The main body for checking health and social care is the Care Quality Commission (CQC), an independent, non-departmental public body formed in 2009 by the amalgamation of the three previous bodies previously responsible. Their reports are all publically available from their website, [www.cqc.org.uk](http://www.cqc.org.uk).

An important aspect of much of this work is the increased expectation that authorities will work together with disabled people and family carers to shape the services of tomorrow. We will be hearing more and more about a process called co-production, the making of policy and plans together with disabled people. Importantly, all of these groups and meetings should include family carers as well. In some areas where this will be very new and may be resisted, this could be challenged.

This ‘how to’ guide sets out the basic decision-making structures and local meetings on policy and practice in your area and the role you can play in influencing their work. The benefits of such involvement can include changing the direction of policy implementation, increasing the input of disabled people and family carers in service planning, better services and support for people with learning disabilities and their carers and the possible funding of local projects. In addition, such work can have a greater influence as views are fed up the structure to both regional and national bodies.

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<sup>1</sup> The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*. Various documents are available at <http://tinyurl.com/vpnow>.

## 3.The structure of learning disability services

Services for people with learning disabilities are mainly provided or bought by the local authority and although central money still goes to the local health service or Primary Care Trust to pay for some of them, much of this is meant to be passed on to the local authority for them to spend (and **it is worth checking** to see and ask about how much is passed on in your area).

The way services are planned and bought varies from area to area. Unfortunately this can mean that:

- Some meetings with similar names have different functions.
- Some meetings with similar functions are called different names.
- Some areas have certain meetings that others will not have at all.

This guide covers the more popular meetings that authorities should have and the things they should be doing, as well as the benefits of being involved.

### Policy - Valuing People Now

Valuing People was the first learning disability policy for 30 years, launched in 2001 to great enthusiasm from people with learning disabilities, it didn't have as much impact as was hoped. Its projected five-year life span was then extended and updated for a further three years by Valuing People Now in 2009.

Valuing People Now modernised and strengthened the policy structures and contained best practice guidance with targets for authorities and services to meet in a number of areas. The work is headed by the Co-National Directors for Learning Disabilities - Anne Williams and Scott Watkin. Their team has been renamed the Valuing People Now Delivery Group. This group works through a team of national programme leads on the various work strands, a cross-government team to take forward Valuing Employment Now (the related employment strategy) and a worker in each region working with the regional Partnership Boards and local areas.

More details can be found on their website, [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk).

### National and local structures

The main driver for better services is the Partnership Board structure. This is headed at national level by the Ministerial Learning Disabilities Programme Board, which includes representatives from the nine regions of England, each with their own Regional Programme or Partnership Board and then to a local Partnership Board in each authority. Family carers and people with learning disabilities should be represented on all of these boards - see figure 1 below.

Alongside these 'professional' boards is a more 'user' led structure that starts with local people and local groups, leading through to a regional group and on to a national group. This group then feeds into the National Programme Board and indeed there should be cross links at all three levels between the groups.

These are called National Forums and there are three of them:

- The National Forum for People with Learning Difficulties
- The National Valuing Families Forum, and
- The National Advisory Group on Learning Disability and Ethnicity (NAGLDE) (See ethnicity networks later).

This later group is a newer addition to the Forums and has a less well developed, or slightly different, structure as a result. Please note that with the election of a new government in May 2010, Valuing People may be coming to an end, and this structure is likely to change.

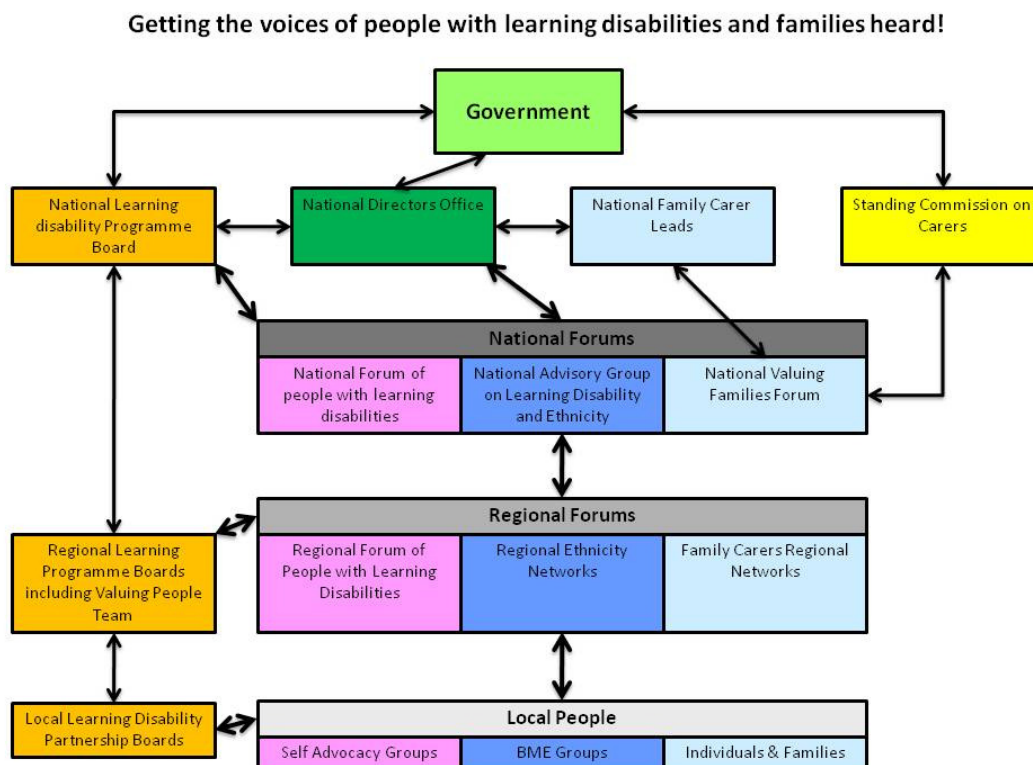


Figure 1

## 4. Local learning disability meetings

### Learning Disability Partnership Boards

Partnership Boards have a key role to play in service design and delivery. Established under Valuing People in 2001, they were seen as a main player in the delivery mechanism, bringing together all the relevant local agencies and stakeholders as well as giving a voice to local people with learning disabilities and their family carers. Their effectiveness was patchy; whilst some became “agents for change”, others were less effective and had varied representation from people with learning disabilities and minimal input from family carers, people with learning

disabilities from black and minority ethnic communities and people with complex needs.

Valuing People Now gave boards another chance and placed a greater emphasis upon them to ensure delivery of the new agenda with new guidance, including best practice examples from around the country<sup>2</sup>.

“The vision in Valuing People Now is that every Partnership Board is central to the strategic planning, commissioning, delivery and performance management of all services as they relate to learning disability in every local area.”

The Valuing People Delivery Plan was published in March 2010. They say it “marks the progress made in the first year. It also recognises that there is still more to do to improve the lives of people with learning disabilities and their family carers. The delivery plan sets out the key priorities for 2010-11, in particular, to improve employment and housing opportunities and better health outcomes for people with learning disabilities and their family carers.” **This is useful to check against performance.**<sup>3</sup>

The Partnership Boards should now be reporting on what is happening locally to the Regional Board and then on to the National Board to enable them to have an overview of progress and see where additional support is required. There is a new guide for Partnership Boards<sup>4</sup> that sets out is expected of them. Again this is only guidance and not mandatory, but boards will be expected to follow it. A central driver is expected to be the annual self assessment report. This has to be signed off by people with learning disabilities and family carers themselves and the guidance sets out a clear process to follow here including what to do if there is disagreement. This is obviously a crucial and powerful tool to use.

The annual report should:

- be clear about the population of people with learning disabilities and their family carers, what their current and future needs are, and how these will be met
- show how this work is closely linked to other work led by its partners
- identify progress and areas where more work is needed
- set out a plan for future work.

## Partnership Board sub groups

Partnership Boards will usually have a number of sub groups. These are often subject specific, looking at a particular area of work such as personalisation (these are sometimes called delivery groups), although they can also be geographically

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<sup>2</sup> The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*. Various documents are available at <http://tinyurl.com/vpnow>.

<sup>3</sup> The Department of Health (2010); *Valuing People Now Delivery Plan 2010-11*. <http://tinyurl.com/vpdelivery>

<sup>4</sup> The Department of Health (2009); *Good Learning Disability Partnership Boards: 'Making it happen for everyone'*. <http://tinyurl.com/guidepb>

specific enabling a greater say from people living in areas separated by some distances in a large county (sometimes called locality reference panels).

People with Learning Disabilities Joint Commissioning Group (JCG) - many areas have Joint Commissioning Groups working on the details and financing of support. These will often include user and/or carer representatives as well as health and local authority representatives and are clearly central when looking at where and how money is spent.

## 5. Local disability groups

### Council disability forums

Many local councils have a disability forum. The aims of such groups are to represent the interests of all disabled people living in the area and enable them to talk about the issues they face. They also provide an opportunity for the council to consult with disabled people on any issues which directly affect them. They often operate under the local authority's equality work and can meet their requirements to consult with people over various issues. These are not always well attended and people with learning disabilities and their carers can be very under-represented.

### Consultation groups

Other areas have set up specific disability groups to act as consultees. For example, BADGE, Bolton Active Disability Group for Everyone aims to include a wide range of disabled people who can be consulted upon relevant matters by health and local authorities.

## 6. Mainstream groups

### Health services

Many people with learning disabilities do not get the health care they need, although this is getting better with more people getting annual health checks and people generally living longer, although still nowhere near the average age.

Historically, non health related services for people with learning disabilities have moved from health to social services. But there are some aspects of care in some areas that are still provided by health and **this is worth checking**.

Perhaps unfortunately, some central money still goes to local health services or Primary Care Trusts (PCTs). Valuing People Now said this should be transferred to local authorities, starting in 2009. Funding for continuing care, forensic services and mainstream health care remains with PCTs, enabling them to focus on the healthcare needs of people with learning disabilities whilst social services can implement the personalisation agenda.

The transfer of money has three guiding principles:

- Fairness - it should be seen as fair by the NHS, local government, people with a learning disability and their families and the Partnership Board.
- Partnership – it should promote partnership working between the NHS, local authorities and Learning Disability Partnership Boards.
- Local solutions – although it is national policy, it is anticipated that local areas will achieve local agreement to how the transfer is agreed and what amounts are transferred.

The amount should be based on the 2007/08 spend and then repeated each year plus inflation.

**It is worth checking** the transfer is happening as there are PCTs that are retaining monies for use in their own priority areas. It may be useful to ask for the full Equality Impact Assessment that has to be done on the funding transfer as well as making sure local governance arrangements are in place.

Good places to ask these questions are the Partnership Boards and Health Boards.

## Health Boards

The Care Quality Commission (CQC) has recommended that Health Boards have a learning disability champion on them to ensure services for people with learning disabilities continue to get better. **It is worth checking** this has happened, who they are and what they are achieving – or indeed filling the vacancy!<sup>5</sup>

## Inspections of health and social care

There are a range of inspections that are undertaken in every area. These range from official CQC inspections to peer audits with health organisations.

Both make use of people who use services and other local carers to give their views on services as well as act as 'Experts by Experience'. **It is worth asking** to be informed of inspections and ask if you can be involved.

## Special health projects

Every so often there are special projects and one off funding for particular activities that are relevant to us. For example The PCT and South Essex Partnership University Foundation Trust have funding from the Department of Health for an 18 month project – 'Better NHS Support for Carers'. This project will help early identification of carers enabling them to get the support and help they deserve. It is important to look after the health and well-being of the carer so that they can continue caring.

This is the sort of project the local champion and Partnership Board should know about as well as introduce any relevant findings in their area. It is, of course,

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<sup>5</sup> The Care Quality Commission (2009) *Specialist inpatient learning disability services*.  
<http://tinyurl.com/cqcspecial>

important that such initiatives include people with learning disabilities and their carers in their work.

## Local Involvement Networks (LINKs)

Each area in England has to have a Local Involvement Network. LINKs replaced the old patient and public forums, and now cover social services as well as healthcare. Although currently rather underused in a lot of areas, LINKs aim to give people a stronger voice in how their health and social care services are delivered.

LINKs are run by local individuals and the groups and independently supported.

LINKs give people a chance to:

- say what they think about their local services
- check how services are planned and run
- carry out spot-checks to see if services are working well.

They will then:

- Use their powers to hold services to account and get results
- Make reports and recommendations and receive a response
- Ask for information and get an answer in a specified amount of time

LINKs meet and talk with people who use health and social care services in their local area to find out about their experiences. **It would hopefully be worthwhile becoming a member.** The core groups should also include care representatives and service user representatives including people with learning disabilities. Some have not filled these roles yet.

## Other groups

During the research for this guide we came across a number of other groups including Health Forums and NHS Community Reference Groups. It is worth checking to see what other groups may exist just in your area.

# 7. Regional groups

## Regional Learning Disability Forums.

The Regional Forums were set up under the original Valuing People and have become well established, although their work is not widely known about unless you are involved. Their main task is to hear what is happening locally from local representatives and pass it on through national representatives to the National Forum. They have increasingly been used to pass information down to local groups as well.

## Regional Learning Disability Programme Boards

Valuing People Now brought in an additional tier to the governance structure in the form of Regional Programme Boards feeding into the national board and the Department of Health delivery group. There are two usual ways into Regional Boards, through local Partnership Boards and local advocacy or carer groups.

The Regional Boards have been set up to help make sure that Valuing People Now happens. Each region will have its own Regional Delivery Plan with actions on each of the four priority areas:

- making sure that Learning Disability Partnership Boards are effective,
- improving health care,
- Valuing Employment Now, and
- helping more people to get a home of their own.

All the regions should be undertaking a 'health assessment' with health services for people with learning disabilities; the results of which will be crucial.

**It will be useful to look at these** and gauge what they say against local experiences.

## Regional Family Carer Network

Family carers who sit on local partnership boards are brought together by a regional family carer co-ordinator. The Regional Family Carer Network nominates two family carers to the Regional Learning Disability Programme Board. The co-ordinator and/or a nominated family carer communicate between the Regional Family Carer Network and the National Valuing Families Forum.

# 8. Ethnicity networks

## National Black Carers and Carers Workers Network (NBCCWN)

The National Black Carers and Carers Workers Network (NBCCWN) is hosted by The Afiya Trust <http://tinyurl.com/blackcarers>. This programme works closely with Carers UK, the Association of Directors of Social Services (ADSS) and the Department of Health (DH). The regional and London networks represent organisations in both the voluntary and statutory sectors. The network holds rotating, regional meetings as well as organising specific meetings for Black carers.

Following the lack of reference to BME carers in the original carers strategy in 1999, "Caring about Carers – A National Strategy for Carers" NBCCWN produced their own guide "We Care Too" with helpful information and contact lists.<sup>6</sup>

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<sup>6</sup> The National Black Carers and Care Workers Network (2002); *We Care Too: A Good Practice Guide for People Working with Black Carers*. <http://tinyurl.com/wecaretoo>

## **Giving us a Voice**

Giving us a Voice is a joint project between BILD (The British Institute of Learning Disabilities), Mencap and ARC (The Association for Real Change). Running until 2011, it works across the country seeking to involve people with a learning disability, their families and carers from minority ethnic communities in regional meetings to inform local policy makers about what they need and expect from services.

They say “there is clear evidence at present that services are not reaching these communities and their families, who are effectively excluded from local participation by lack of contact, language difficulties and the belief that no-one will listen. *Giving us a Voice* is a systematic way of tackling this problem and challenging local statutory bodies and providers to sign up to the *Charter for Inclusion* which the project will produce from meetings with users and families.

Eight regional summits will also inform future decision-making about services for this group and encourage participation in local consultations.” For more information see [www.arc.org.uk](http://www.arc.org.uk).

## **The National Advisory Group on Learning Disability and Ethnicity (NAGLDE)**

NAGLDE’s aim is to ensure that people with learning disabilities and their carers from minority ethnic communities get equal access to services that are right for them. To do this they:

- Aim to influence government plans nationally and locally
- Give advice on government plans that affect the lives of people with learning disabilities from minority ethnic communities
- Carry out surveys and projects that will help to influence government plans
- Talk to the National Learning Disability Programme Board
- Work with Valuing People Now
- Support the Learning Disability Ethnicity Network (ARC)
- Support the Ethnicity Training Network
- and support other organisations that promote the rights of people with learning disabilities from minority ethnic communities.

For more information see <http://tinyurl.com/naglde>.

## **9. Enabling people to be involved**

It is now a requirement of local authorities and health authorities that those who use services should be not only consulted but also involved in policymaking. Family carers and people using services often need preparation for this role. Many areas have Partners in Policy Making courses run over a number of weeks, equipping people with the skills and experience to effectively take part. For more information see [www.partnersinpolicymaking.co.uk](http://www.partnersinpolicymaking.co.uk).

## 10. References, further reading and contact details

The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*. <http://tinyurl.com/vpnow>

The Department of Health (2010); *Valuing People Now Delivery Plan 2010-11*. <http://tinyurl.com/vpdelivery>

The Department of Health (2009); *Good Learning Disability Partnership Boards: 'Making it happen for everyone'*. <http://tinyurl.com/guidepb>

The Office for Disability Issues (2010); *Making the most of partnership boards*. <http://tinyurl.com/pbodi>

The Care Quality Commission (2009); *Specialist inpatient learning disability services*. <http://tinyurl.com/cqcspecial>

The National Black Carers and Care Workers Network (2002); *We Care Too: A Good Practice Guide for People Working with Black Carers*. <http://tinyurl.com/wecaretoo>

The National Black Carers and Care Workers Network (2007); *Beyond We Care Too: Putting Black Carers in the Picture*.

The Department of Health (2009) *Use of Resources in Adult Social Care - A guide for local authorities*. <http://tiny.cc/resicare>

Various documents relating to Valuing People Now are available at <http://tinyurl.com/vpnow>.

Further information can be found on The Princess Royal Trust for Carers' three websites [www.carers.org](http://www.carers.org), [www.carers.org/professionals](http://www.carers.org/professionals) and [www.youngcarers.net](http://www.youngcarers.net), and on Crossroads Care's website, [www.crossroads.org.uk](http://www.crossroads.org.uk), or by contacting Cath Baker, Policy and Development Officer (Learning Disabilities), telephone 01568 760027, email [cbaker@carers.org](mailto:cbaker@carers.org).

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