

Supporting Learning Disability Partnership Boards to Implement the National Carers Strategy

This booklet aims to tell Learning Disability Partnership Boards more about:

- The National Carers Strategy called 'Carers at the Heart of 21st Century Families and Communities'
- What to do to make sure that local plans for all carers include carers of people with learning disabilities and carers with a learning disability.



“Valuing People Now says that families play an important role in supporting people with learning disabilities: they ‘offer a lifetime of involvement, support and advocacy’. Families also have an important role to play in making Valuing People Now happen in their local area.

*The **National Carers Strategy** says that family carers should be supported in their caring role and that they also have a right to a good quality life of their own.*

We have a real opportunity through joined up work on the National Carers Strategy and Valuing People Now to make a difference. It is very important that Learning Disability Partnership Boards use the information in this booklet to link up with the implementation of the National Carers Strategy in their local area and ensure that family carers of people with learning disabilities benefit from, as well as contribute to the development of, mainstream carers’ initiatives.”

- Philippa Russell DBE & Cally Ward



Philippa Russell DBE is the Chair of the Standing Commission on Carers. Her job is to make sure the Government is listening to what carers need and want, and that everyone is working together to make sure the Carers Strategy makes a real difference to all carers.



Cally Ward works for the Valuing People Team and chairs the National Valuing Families Forum. Her job is to make sure that the needs of family carers of people with learning disabilities are recognised and linked in with work happening on Valuing People Now.

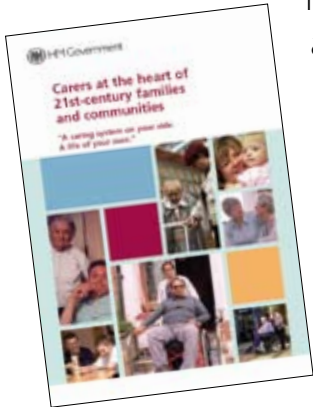
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Part 1:

Joining up the National Carers Strategy & Valuing People Now

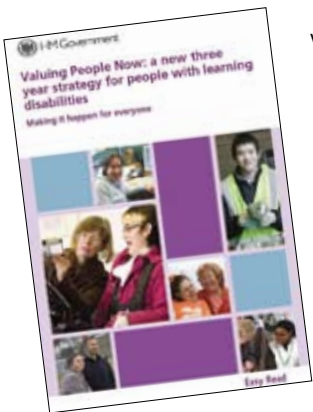
The big message in the National Carers Strategy



The Government recognises that family carers play a very important role supporting millions of people across the country and that health and social care systems would find it almost impossible to manage without their contribution. Many carers' experience of these systems is not very positive and it can feel like a constant struggle to get the right support. Many carers do not get the opportunity to have a life of their own alongside being a carer. The Government wants to change this situation. Carers should be able to experience a system that is on their side and be supported to have a life of their own alongside their caring responsibilities.

The National Carers Strategy is not just about carers of people with learning disabilities: it is about all carers.

The big message in Valuing People Now about family carers



Valuing People Now recognises that many people with learning disabilities live at home with their families or get lots of support from their families wherever they may live. Valuing People Now says that supporting family carers is central to supporting people with learning disabilities to have more choice and control over what happens in their lives. Valuing People Now says that there is a lot that should and could happen to make things much easier for families. Families should be seen as expert partners and their role and expertise should be valued.

Making the link between the National Carers Strategy and Valuing People Now

Learning Disability Partnership Boards need to understand what the National Carers Strategy says so that any work they are doing with people with learning disabilities and their families is joined up with any work to support carers in their local area.

Everyone has a role to play in making this happen: it should not be only the family carer representatives on the Partnership Board who speak up about carers' issues. All members of the Partnership Board need to 'think families' and make sure they link with local and regional initiatives for carers.

Who are carers?



A carer is someone of any age who provides unpaid support to family or friends whose health or wellbeing could suffer without this help. This could be caring for a relative, partner, child or friend who is ill, frail, disabled, has learning disabilities, mental health or substance misuse problems.

Lots of people who are carers do not realise they are carers. They are just doing what needs to be done to support the person they care about.

It can also be confusing because care workers who are paid to care for people sometimes get called 'carers'.

Family carers of people with learning disabilities



Family carers of people with learning disabilities have usually been carers for the lifetime of the person they care for. These carers are often described as having a **lifetime experience of caring**. This may mean they have been caring for 30, 40, 50 or more years. They have been through lots of different experiences as carers and had to cope with many changes. Most family carers of people with learning disabilities care for more than 50 hours a week – helping with personal and social care, as well as just being around to prompt people and make sure they are staying safe. Even if someone has moved away from home, many family carers stay very involved.

Carers with learning disabilities



There are many people with learning disabilities who are carers. They may be doing a lot to support their elderly relatives, a partner or friend. They have the same wishes and needs as other carers, but often they may find it even more difficult than other carers to be recognised for what they are doing and to be offered any information, advice and practical support.

Some facts about all carers:

- The 2001 Census found 5.2 million carers in England and Wales
- Carers save the economy an estimated £87 billion every year

- 65% of carers of working age give up work
- 21% of carers providing care for over 50 hours each week say they are not in good health.

Some facts about carers of people with learning disabilities

- An estimated 974,000 adults with a learning disability live in England
- 64% of people with learning disabilities live with their families
- An estimated 40% of people with learning disabilities are cared for by a parent over 60 years old
- One third of people with learning disabilities living at home are supported by a relative who is over 70 years old.

Main Points:

- The Government knows they need to value carers and work with them as partners. It would be very difficult for the Government to look after everyone if carers were not doing so much unpaid caring
- The Government has a plan about how people looking after other people should be supported. The plan is the National Carers Strategy
- The National Carers Strategy is a 10 year plan to make things better for carers
- More than 5 million people are carers in England and Wales
- People sometimes get confused about who carers are. Carers are usually looking after a family member, partner or close friend. They are not paid for caring. Care-workers or support workers are paid to look after people
- Many of the aims of Valuing People Now and the National Carers Strategy are the same
- Most people with learning disabilities live with their families or have support from their family. Plans for carers in your area need to include these families
- Plans for carers in your area should include carers who have a learning disability too
- Family carers of people with learning disabilities often care for a long time
- Carers who have a learning disability often do not get the help they need
- Partnership Boards have a very important job to make sure that the work they do links up with other work that is happening for carers.



Part 2: What the Government is already doing to support carers

To be able to make the most of the new National Carers Strategy, it is important to understand some of the work that is already happening to build up stronger support for carers:

1. In 1999, the Government started giving the **Carers Grant** to Local Authorities to help them increase support to carers. Between 2009 and 2010, the Government gave £240 million through the Carers Grant and this is due to rise to £256 million in 2010 to 2011.
2. In 2000 the **Carers and Disabled Children Act** became law. It said:
 - Councils could provide services to carers directly rather than only through the person they care for
 - Carers had a right to an assessment independent of the person they care for
 - Local authorities could make direct payments to carers
 - Councils could be more flexible in how they provided short breaks.
3. In 2004 the **Carers (Equal Opportunities) Act** became law. It said:
 - Councils have a duty to tell carers about their right to an assessment of their needs
 - When assessing a carer's needs, councils must take into account if a carer works or wants to work, or if they wish to start or continue any education, training or leisure activities
 - Local authority departments should work together to provide services most useful to carers.
4. Other law and policy already in place that helps carers includes:
 - The 2006 **Work and Families Act** gives carers of adults the right to ask for flexible working.
 - **Our Health, Our Care, Our Say** has led to the Government giving £2.8 million a year to fund a national information service for carers.
 - Setting up **Caring with Confidence**, a training programme for carers to empower and enable them in their caring role.
 - The Government has a programme, called **Aiming High for Disabled Children**, to

improve support to children and their families. This included £370 million between 2008 and 2011 to improve short breaks.

- From October 2007 the Government also gave an extra £25 million a year to local authorities for **emergency support** as part of the **New Deal for Carers** that is now included in the **Carers Grant**. The money was to help them work out plans with carers to cover emergencies that might happen. Wherever possible, the plan should be that the person stays in their home with support if the carer has an emergency. Plans need to be made with both the carer and the cared for person wherever possible.

Did you know?

Carers Direct is the new national information service for carers. There is a website with lots of information to help carers manage their lives around caring. The national telephone advice line offers free and confidential advice to carers at 0808 802 0202. The website address is **www.nhs.uk/carersdirect**

You can find out more about **Caring with Confidence** in your area by visiting the website at **www.caringwithconfidence.net** or calling 0800 849 2349.

Many areas have used the grant for emergency support to set up local schemes to respond to carers' emergencies 24-hours a day. Carers UK has information about some of the schemes in local areas at **www.carersuk.org**

The Valuing People Team is sending guidance to Partnership Boards planning with families for emergency support. This will be available to download in late 2009 at **www.valuingpeople.gov.uk**

Main points

- The Government gives money to local areas to make things better for carers. This is called the Carers Grant.
- Carers have more legal rights than they used to.
- A new national information service has been set up for carers.
- The Government has included money in the Carers Grant for local areas to plan how to help families get the right help when they have an emergency.



Questions to ask:

- How much Carers Grant does our Local Authority get?
- How is this Carers Grant spent on support for family carers of people with learning disabilities and carers with learning disabilities?
- Could this money be spent in a better way, such as holiday schemes, befriending or support services for carers?
- Who is responsible for making sure council departments, such as housing and leisure, work together to support carers? How are they doing this?
- How can carers of people with learning disabilities in our area take part in the Caring with Confidence training programme?
- Is the training accessible for carers who may have a learning disability?
- How has the Emergency Care Cover money been spent in our area?
- How many carers of people with learning disabilities now have plans for emergencies in place?

Part 3:

Carers at the Heart of 21st Century Families and Communities – the new National Carers Strategy (2008)

The new National Carers Strategy sets out the plans for all carers until 2018. It builds on the work already happening to support carers. The Strategy sets out things that will happen in the next 3 years and in the next 10 years.

This Strategy says if things are going to improve for carers then lots of work needs to be done. The Carers Strategy's aims overlap with Valuing People Now and other Government strategies. For example, Valuing People Now says that better health, personalisation, work and having a life of their own are some of the main goals for people with learning disabilities and the National Carers Strategy says the same thing for carers.

Like Valuing People Now, the new Strategy for supporting carers is not something separate – it is part of the work that is all about supporting people to have more choice and control over their lives and improving the NHS, the benefits system and social care and support. Everyone should be encouraged to recognise and value carers.



What your Partnership Board needs to know about the National Carers Strategy

The important areas of action in the new National Carers Strategy are described under the following headings:

- a. Assessment
- b. Joined up working
- c. Workforce
- d. Improving information for carers
- e. Breaks from caring
- f. Personalisation and self directed support
- g. Technology
- h. Housing, leisure and transport
- i. Employment and training
- j. Health and well being

a. Assessment



- It is really important for services to work together better to respond to the needs of the person being cared for and the carer.

The Common Assessment Framework (CAF) is being developed for adults to make sure information that everyone needs to know about a person is shared between organisations (with their consent). This should mean carers only need to tell their story once rather than repeat it to different workers. It should help to make sure people get better support.

Did you know?

The Valuing People Team has produced two tools to help carers of people with learning disabilities and carers with learning disabilities get the most out of carers' assessments. Both tools include a checklist that helps people think about the things they do all the time in case they forget these are part of their caring role.

Carers' Assessments: What's in it for you? can be downloaded from the families section on the Valuing People website at www.valuingpeople.gov.uk

Being a carer and having a carers' assessment can be downloaded from the Valuing People website at www.valuingpeople.gov.uk or from the Foundation for People with Learning Disabilities website at www.learningdisabilities.org.uk

b. Joining up work between health and social care

Health and social care services need to get better at working together to make sure carers get good support.

New Action: In 2009-2011 demonstrator sites* will be run to look at the ways primary care trusts (PCTs) can support carers better. The sites will focus on good practice that includes:

- Involving carers in diagnosis, care and discharge planning
- Providing more support for carers at GP practices
- Working with social care services and the voluntary sector to provide support that is more flexible.



* For a full list of demonstrator sites please visit:

http://www.dh.gov.uk/en/SocialCare/Carers/DH_094301

c. Workforce



Workers from a range of organisations, including health, social care, housing, benefits and employment services, need to recognise carers and treat them as expert partners in care. Also, carers need to have confidence that any support provided by paid care workers is of high quality and will meet the person's needs properly.

New Action: The Government is putting money into training a range of workers, including health and social care staff, so that they support carers better when they come into contact with them as part of their work and when making local decisions about services.

d. Improving information for carers



Carers need easy access to detailed and up-to-date information at the right time. Information needs to be available in different ways so it is accessible to everyone, including carers with learning disabilities and people whose first language is not English.

New Action: From 2009 -11 the Government is giving local areas more money to make sure carers have good quality, up-to-date and accessible information.

Carers should have the opportunities and time they need to have a life outside their responsibilities as a carer:

e. Breaks from caring



New Action: From 2009 -11 the Government will give PCTs £150 million which they can use to provide breaks for carers. They have to draw up joint plans with their Council, after talking to carers and voluntary organisations, to show how the new money and the Carers Grant will be used.

New Action: In 2009 -11 there will be some demonstrator sites to encourage new ideas about planning and delivering breaks services in a personalised way.

f. Personalisation and self directed support



Carers and the people they care for should receive support that fits around their needs, rather than having to fit into services. Support services should be 'personal' to their needs, or 'personalised'. Carers, and those they care for, should be able to choose to have personal budgets in order to have more flexibility, choice and control about the way support is provided.

g. Technology



There is lots of special equipment being developed that may help people to be more independent. Some may reduce carers' anxieties and the demands they experience. Examples would be gas sensors in the kitchen, alarms if someone is having a seizure in bed and sensors on doors. This may be called Telecare. The Government has already given money to councils for this sort of technology. It is important that carers have the equipment that could improve their peace of mind and enable them have more free time away from caring.

h. Housing, leisure and transport



Living in a place that is right for a person's needs is really important. When things are going wrong with housing then things can become very stressful for everyone, including carers. Housing providers need to work more closely with health and social care professionals to join things up for families.

Some councils run schemes that recognise the value of carers by offering discounts on things like transport and leisure for carers, even if the person they care for is not with them. Lots of carers are on a very low income and do not get a lot of time to themselves, so these sorts of schemes are really popular and they can help carers to be less alone.

New Action: The Government will work with councils to make sure that this sort of good practice for carers is available in more places.

i. Employment and Training



Carers who want to work need to be supported to get jobs and keep them. Employers need to be more flexible about the way they support workers who are also carers. People who are no longer caring need support to be able to find a job, especially if they have been caring for a long time.

Many carers find it hard to take up training and education opportunities because they are too busy caring. This makes it harder for carers to compete for jobs.

New Actions: Jobcentre Plus Care Partnership Managers will be trained to help carers get into employment. The Government will also produce a good practice guide for all employers on the benefits of employing carers.

The Government will encourage more flexible opportunities for life-long learning to be made available to carers. From 2010 there will be national skills accounts to help people choose how, and what, they learn.

j. Health and Well-being



Carers need to be supported to stay mentally and physically well and should be treated with dignity. There is a lot of good work happening to improve the health support for carers in GP practices and other health settings, but there is still a lot to do.

Caring should not make people unwell, but people are often under lots of physical and emotional pressure.

Carers should have time to look after their own health and not put off treatment and appointments because of time pressures and exhaustion. The funding from the Government to councils for emergency breaks should be used to help carers and individuals plan for what will happen if the carer is unwell or needs medical treatment, such as having a planned or emergency operation.

New Action: PCTs are trying out health checks for carers in a number of areas. The Government is also working with doctors to develop and test a training programme about carers for GPs.

Making it happen

The Standing Commission on Carers will be very important in making sure that the Carers Strategy makes things better for carers. Changes are all meant to happen in the next ten years, but some of them are planned to happen by 2011.

Did you know?



Putting People First without Putting Carers Second reminds people that carers needs must be considered while making sure people can have choice and control over how their needs are met. This includes carers with learning disabilities. The booklet was produced by The Princess Royal Trust for Carers, Crossroads Care and others. It sets out the challenges of making the personalisation agenda work for families, and offers examples for meeting those challenges.

Download a copy from www.carers.org/professionals

Part 4:

Questions to ask to make the National Carers Strategy happen

These are a list of questions that your partnership board can use to check what is happening in your area and to create change for carers.

Assessment

Carers have a right to ask for an assessment of their needs as a carer. This is called a carers assessment. Services also need to share information about carers. This will help carers to get better support.



Questions you could ask:

- How does our Council make sure that carers of people with learning disabilities and carers with a learning disability know about their right to an assessment of their needs?
- What services have been provided directly to carers because they have had a carers' assessment?
- Are there differences between what carers are asking for and what they get? How is this information collected and reported back?
- How many carers with learning disabilities have had a carers' assessment in the last year?

Working together

Health services and social services need to get better at working together to support carers.



Questions you could ask:

- Who has the lead responsibility for carers in our local Primary Care Trust, in our Council and in our local hospitals?
- How do these workers get information about the needs of carers of people with learning disabilities and carers with learning disabilities? How can we give them better information? Do they come to the Partnership Board?
- Is our Primary Care Trust running one of the demonstrator sites? If it is, how can we be involved?

Workers

There needs to be good training for workers about how to support carers



Questions you could ask:

- What training is happening or planned for the workforce around supporting carers in our area?
- Are carers of people with learning disabilities, including carers with learning disabilities, providing some of the training?
- Valuing People Now also says it is really important to train workers better to understand the needs of people with learning disabilities. What links can we make between our workforce plans and carers' workforce plans in our area?

Information

Carers need to get good information when they need it.



Questions you could ask:

- How do we make sure carers of people with learning disabilities and carers with a learning disability know where to go for information and advice in our area?
- Who is responsible for making sure that information for carers is of good quality, up-to-date and accessible in our area?
- Do we know what information carers of people with learning disabilities and carers with learning disabilities would find most useful and accessible? If not, how do we find out?
- How can we keep working together to make sure carers have the right information when they need it?

Short breaks / respite

Carers need breaks from caring. Local areas need to work together so families can choose a break that suits everyone. There is money being given to PCTs and councils to help make this happen.



Questions you could ask:

- Is the extra money given to PCTs for breaks being used to support carers of people with learning disabilities and carers with learning disabilities?
- What has the PCT done to consult with these carers and voluntary organisations about what is needed and what has been planned?
- Is our area one of the demonstrator sites for breaks? If so, how can we work together to plan creative breaks that people want?
- How can we work with Children and Families services to make sure that families of young people get the right breaks as they become young adults?

Personalisation

Carers need more choice and control over the support they get.



Questions you could ask:

- What is being done to support carers of people with learning disabilities, and carers with learning disabilities, to use self directed support (such as information, advice, advocacy, brokerage)?
- How many people with learning disabilities in our Council are using self directed support and have a personal budget?
- Do family carers feel that they have been fully involved in the decision to use a personal budget?

Technology

Carers should be able to get equipment and technology to help them.



Questions you could ask:

- How many people in our council have access to Telecare and other special equipment to help them to be independent and safe?

Housing, leisure & transport

Support for carers needs to be across all services, including housing, leisure and transport.



Questions you could ask:

- Who is responsible for making sure that our housing, leisure and transport service are working together for carers? Do we need to do more to make sure that person understands the needs of carers of people with learning disabilities and carers with a learning disability?
- Is our council planning a carers' recognition scheme? How do we make sure that carers of people with learning disabilities and carers with learning disabilities can benefit from it?

Employment and Training

Carers need the right support and information to be able to work, or be in education, and still be carers.



Questions you could ask:

- Do family carers of people with learning disabilities, as well as carers with learning disabilities, get information about their rights and support if they have a paid job or are training?
- Does the work our Partnership Board is doing around different strategies recognise that carers may be (or may want to be) working or training? For example, this may mean that support needs to be flexible around working hours and courses.
- Are there any arrangements to provide replacement care when a family carer is working?

Health and well-being

Carers need to get the right support to be healthy and happy.



Questions you could ask:

- Is our area a demonstrator site for carers' health and well-being checks? How can we make sure carers of people with learning disabilities and carers with learning disabilities are made aware of them?
- Can we talk to GPs about the health needs of carers when talking to them about health checks for people with learning disabilities?

Overall Key Points

- The National Carers Strategy and Valuing People Now share many aims
- Making things better for carers of people with learning disabilities will help people with learning disabilities to have a better life
- Learning Disability Partnership Boards have a key role to make workers, services and organisations understand the needs of carers of people with learning disabilities and carers with a learning disability
- This work will lead to new and exciting partnerships with others outside services for people with learning disabilities.

For more help:

The Princess Royal Trust for Carers and Crossroads Care have a range of resources available to support Learning Disability Partnership Boards to put the Carers Strategy into practice, and to support their work with carers. These include:

- The 'Carers Wheel': a draft model of how to deliver comprehensive carers services locally
- Carers Commissioning Guidance (Autumn 2009)
- Forthcoming toolkit for staff and volunteers working with carers of people with learning disabilities and carers with learning disabilities (Autumn 2009)

All of these documents are available, or will be available soon, from The Princess Royal Trust for Carers professionals' site, **www.carers.org/professionals**

For more information on the two local services provided by our two networks, please see www.carers.org and **www.crossroads.org.uk**



If you would like to read a full copy, a summary, or an easy read version of the National Carers Strategy, they can be downloaded from www.dh.gov.uk or by phoning 0870 600 5522.

For a full list of demonstrator sites please visit http://www.dh.gov.uk/en/SocialCare/Carers/DH_094301

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It was commissioned by the Family Carers programme of Valuing People Now through their work with The Princess Royal Trust for Carers and Crossroads Care.



The Princess Royal Trust for Carers is the largest provider of comprehensive carers support services in the UK. Through its unique network of 144 independently managed carers' centres, 85 young carers services and interactive websites – www.carers.org and www.youngcarers.net - the Trust currently provides quality information, advice and support services to 354,000 carers, including 20,000 young carers. We have a specialist section on our main website for professionals working with carers: www.carers.org/professionals



Crossroads Care provides breaks and support for carers. Our aim is to relieve the stress experienced by carers, and children and adults who have care needs as a result of disability, illness or age by offering a quality respite service through the provision of community-based carer support workers.

www.crossroads.org.uk



The **Foundation for People with Learning Disabilities** works to promote the rights, quality of life and opportunities of people with learning disabilities and their families. We carry out research, promote the rights of people with learning disabilities, improve services and spread knowledge and information.

www.learningdisabilities.org.uk



The **Sharing Caring Project** supports family carers of adults with learning disabilities in Sheffield. By providing advocacy, accessible information, group and individual support, the project aims to support families to in their caring role and enable them to prepare for the future with greater confidence.

www.sheffieldmencap.org.uk

Further copies available from the Valuing People website: www.valuingpeople.gov.uk

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