

Newsletter

Summer 2007

Valuing People
Support Team

This newsletter is about some of the important things families of people with learning disabilities need to know

It has been a busy year since the last Valuing People Support Team Family Carer Newsletter. There is so much to share that we have decided we need two newsletters this year!



In this newsletter we will be telling you about some of the important things family carers need to know. This includes:



- What Valuing People Refresh means for family carers
- The 'New Deal' for Carers promised by the Government
- The National Family Carer LINKS group which helps the Task Force and the Valuing People Support Team know what is important for families.
- An information round up on some of the things happening for families.
- An update on work to support people with learning disabilities who are carers.

Later this year, the second Family Carer newsletter will take a look at In Control, Individualised Budgets, Direct Payments and Self Directed Support as we know these are 'hot topics' for many family carers.



Cally Ward

Valuing People Support Team

Valuing People Refresh



Ivan Lewis, the Minister for Care Services, has said that *Valuing People* needs to be refreshed. He has asked Rob Greig to put together a report that will say what still needs to be done to make people's lives better. The report will be used to help people keep working on what still needs to be done to make *Valuing People* happen and set new targets.

This is good news for families. Cally and the National Family Carer Links Network (see pages 8-9) have already been talking about some of the things that Partnership Boards need to do to 'refresh' *Valuing People* for family carers.



Partnership Boards need to be asking:

- How well have we done in doing all the things in the *Valuing Families* Toolkit?
- Have we invested in family leadership? Can we show how we involve families in local planning and decision making and where it has made a difference?
- Do we make sure family carers get enough breaks?
- The National Family Carer Links network, are meeting on the 23th July to tell Rob Greig what families are saying should be included in his report. If you have something important to say, contact the person who is representing your Valuing People regional family carer network (see pages 9-12).



Valuing People is being looked at again. Family carers need to tell Rob Greig what is most important for them.

A New Deal for Carers!



Being the family carer of a person with a learning disability is a constant balancing act between wanting to get the very best for that person and needing to have a life of your own and stay healthy. This is what is meant by **family centred support** – which takes everyone's needs into account because we are **all** important.

It is important family carers of people with learning disabilities make sure they get the best support they can so that they can support their family member to get a better life.



Our Health, Our Care, Our Say promises a 'New Deal for Carers' and changes the way people can have their say in local services.

The New Deal for Carers was announced in February 2007:

- £25 million for carers' **emergency schemes**
- £5 million for **an Expert Carer programme** for training and supporting carers
- £3 million for a national **information and advice line**

The government wants to do a lot more to support carers to get the right help and support

Count Us In! The 2011 Census

The last census asked people if they were a carer. This provided lots of useful information about carers needs locally and nationally. This question might not be included in 2011's census.



Carers can take action by writing to: Ian Cope, Census Director, Office for National Statistics, Segensworth Road, Titchfield, Fareham, Hampshire PO15 5RR.

It's important to know how many people are caring

Help shape the future for Carers



The Government are consulting on how to revise and update the **National Strategy for Carers** which was first published in 1997. This is a really great opportunity for family carers to get involved and help shape the governments thinking about what should be included.



The government are asking what needs to be included in a new Carers Strategy. *'What would make a positive difference or improve your life as a carer?'* Have your say at: www.newdealforcarers.org

Carers UK are also holding consultation events in June and July and you can find out more at www.carersuk.org

The Valuing People Support Team will be helping to organise events for family carers

The government is asking carers to tell them how they should be helping them more. It's important this includes families of people with learning disabilities.



New Deal or Raw Deal? What does the future hold for carers in the UK? Carers UK is organising a big debate in London on the 8th November to try to influence national policy. To book a place contact Carers UK at www.carersuk.org or ring 020 7490 8818

Carers can go to London to say how carers should be supported

Linking Up With All Carers



Linking in with the mainstream carers' movement is very important. Marion Price, a family carer from Surrey, wrote to Cally Ward to tell her what a difference joining things up makes. These are some of the main points Marion makes:



'I feel that it is extremely important for carers of people with a learning disability to know what is going on in their local and national generic carer groups.

The County Council has a Lead Officer for Carers. There are Area Carer Strategy Groups and a County Strategy Group. These are made up of people from the Voluntary Sector, Statutory Sector, Carer Support Workers and obviously Carers. The Area Groups have a say in some of the Carers Grant is spent. They keep an eye on successful bids to make sure things are moving forward well. Members of the groups have had a say in the Carers Strategy and the Carers Charter which has been signed up to by the Statutory Sector and will be published in June.



Carers who sit on the Partnership Board may not have time to participate in these activities but I think that it is important that there are representatives of carers of people with a learning disability on all the groups, so they can share information'.

It is important for carers of people with learning disabilities to work with carers of other people too

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Join Carers UK



Carers UK is offering **free membership** to carers, former carers and others supporting their aims. If you join you can get the 'Caring' newsletter every three months and use their free telephone advice-line amongst other things.

CARERS UK
the voice of carers

Sometimes it can feel that the needs of family carers of people with learning disabilities are not noticed as much as other carers. Joining Carers UK will help make sure that the needs of this group of carers are represented more strongly.

To join Carers UK:



020 7490 8818



www.carersuk.org

If you are a carer you can join Carers UK for free

Short Changed



Carers UK have recently launched a new campaign which calls for a major rethink on how society values carers and the financial hardship faced by so many. One of its major aims is to call for a review of the Carers Allowance.



To find out more and pledge your support to the campaign, visit www.carersuk.org

Carers UK want to make sure carers have enough money

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Partnerships Beyond The Boardroom...

This new Guide is being produced by Inclusion North to help Partnership Boards think about how to work with other organisations who make important decisions locally.



The Guide will:



- share information about how Boards have been able to work with other groups to get issues for people with learning disability on everyone's agendas
- show how it's very important to raise awareness in all organisations about what support people with learning disabilities need to for them to be included.

If your Partnership Board is working with any outside agencies on issues such as employment, transport, leisure, citizenship or any others, please contact Alison Cowen on:



01904 330606



alison.cowen@ntlworld.com

Work is happening to help Partnership Boards work better with other groups to help people with learning disabilities

Supporting Families to Make a Difference:

Developing a framework of good practice



A Pack is being written to support family carers on Partnership Boards and other groups to speak up and influence services and support. The pack will offer a framework of good practice for supporting families to make a difference. It will include lots of useful information, practical suggestions and examples of what can work for families.

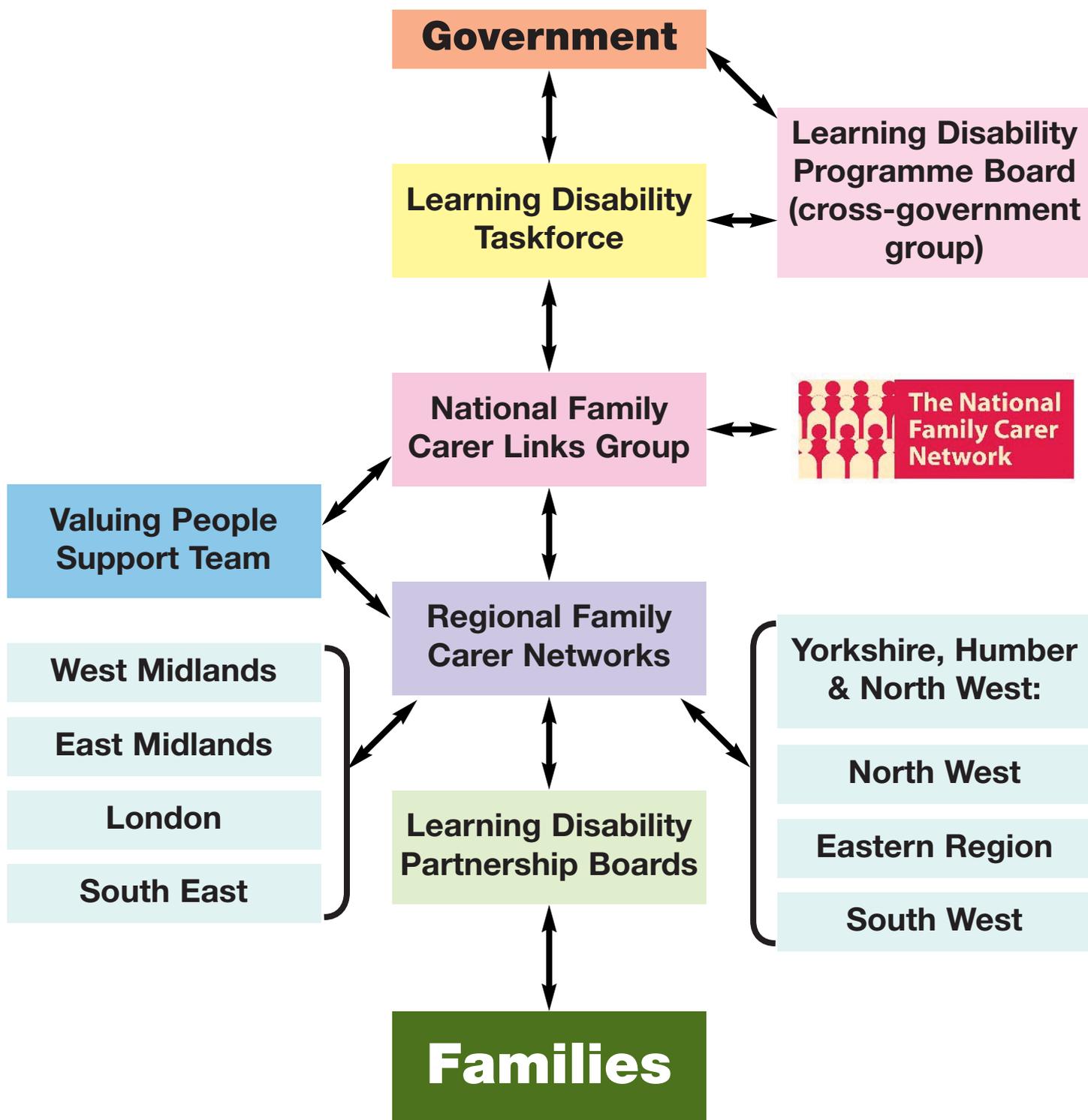
The Valuing People Support Team is hoping this pack will be ready to pilot in July and be sent out by the end of the summer.

A new pack to help family carers on Partnership Boards speak up is being written.

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Linking up the Voices of Family Carers



Linking up the Voices of Families



The **National Family Carer Links Group** provides a direct link between family carers representing families at Partnership Board level right through to the family carers who are part of the Task Force which feeds in to the government. The diagram on page 8 shows how everything links together.

Family carers can be part of their local and regional networks. The Regional Networks and National Family Carers Links Group are funded by the Valuing People Support team which is part of the Care Services Improvement Partnership (CSIP).



The dates for the Regional Networks and the National Links Group are changing so that the family carers on the Task Force have the most up to date information from local families.

Organisations and carers groups working with families can link in to the National Links Group through the National Family Carer Network.



Ivy Penny, representative of the Yorkshire, Humber and North East Regional Family Carer Network says:

“Originally I felt I was a voice in the wilderness but having joined the Partnership Board and then the Regional Family Carer Network, I never expected to find myself in London at the National Family Carer Links Network speaking up for the concerns of carers in my region. At last I feel listened to and people are taking notice of what’s being said”

There is a new group called the National Family Carers Links Groups. This makes sure that things that are most important for family carers can be heard by everyone

The Learning Disability Task Force

The Learning Disability Task Force was set up in 2001 when the Government published *Valuing People*. The Task Force's job is to check that the things in *Valuing People* are happening and are helping to make people's lives better. There are four family carer representatives on the Task Force; Vicki Raphael, Les Scaife, Janet Chierchia and Kauser Ahmed. Vicki and Kauser are also part of the National Family Carer Links Group

Vicki says: *"Knowing that we now have a direct link to the larger network of family carers really helps us feel listened to and more confident to put things forward at a national level. What's best is that we can now more easily feed things back to families and that makes a big difference to us"*



The Learning Disability Programme Board

The Learning Disability Programme Board works across different Government departments. The group has been set up by Ivan Lewis, the Minister for Social Care, to look at how the aims of *Valuing People* can be refreshed and to make sure issues raised at the task Force are taken up properly.

People on the Programme Board include senior civil servants from the main Government departments. This means that decisions are taken at the highest possible level and are more likely to result in action. Karen Flood represents the Learning Disability Forum and Kauser Ahmed represents family carers.



Kauser is a family carer representative on the Learning Disability Task Force and the National Family Carer Links Group. Kauser would love to hear the views of other family carers about the Programme Board:

Email Kauser at



Kta385@googlemail.com

Family Carers are very involved in national work speaking up for people with learning disabilities and their families.

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Getting Involved in the Regional Family Carers Networks



West Midlands Family Carers Network

We meet three times a year in Birmingham and our meetings are jointly for family carers involved in speaking up in local areas and paid workers whose role is to support families.



Flick Pennal, who organises the Network on behalf of the Valuing People Support Team says: *“Whilst informal, friendly and fun, the meetings are always good for sharing up-to-date information and raising issues that can be passed upwards”*.

To be added to the mailing list, contact Julie Steadman:



01743 360641



julie.steadman@shropshire-rcc.org.uk

South East Family Carers Network

Our network meets 4 times a year (usually in London). Our meeting is usually divided into two main parts: an agreed theme and speaker (our Regional Advisor from the Valuing People Support Team).



Viv Cooper, who organises the Network on behalf of the Valuing People Support Team says: *“We’ve got a core group of people who attend regularly and those who can’t come to meetings are kept up to date through the minutes, papers and a newsletter”*.

For more information and to join the mailing list for the Network, contact Viv Cooper:



07847 013179



vivien@thecbf.org.uk

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Yorkshire, Humber & North East Regional Family Carers Network

This joint Network meets four times a year in York. It is organised by the Sharing Caring Project (SCP) and is always attended by the Valuing People Support Team Regional Advisors. The meetings are aimed at family carers involved in speaking up locally and workers supporting family carers to speak up. Around 40 people attend regularly and around 120 people receive regular information and notes from the meeting.



Ray Venus, a carer from the North East and the representative from the Network to the National Links group says: *“It feels really positive to be able to network with carers from other areas – it helps me feel less isolated”*.

For more information and to join the mailing list contact the SCP:



0114 2758879



scpoffice@sharingcaring.org.uk



Eastern Region Family Carers Network

The Regional Family Carer Network meets four times a year in Cambridgeshire – the most central place for this big region. Family carers and representatives from organisations supporting families are all welcome.



Santo Mann says *“the good thing about coming to the Regional Network is that we see things that we are achieving and not achieving around the region and we can learn from each other. It’s an even more useful group now that we are linked in nationally as well”*.

For more information, contact Laura Potter:



01449 616187



easternregion@valuingpeople.gov.uk

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London Family Carers Network

The London Regional Family Carers Network meets four times a year. London also has a Big Partnership Board which meets to discuss issues important to Londoners, like transport. There are four family carer reps on the Big Partnership Board.



Jean Willson is currently representing family carers from the London area and has been working on behalf of families in Islington and in lots of national groups too.

To be added to the mailing list, contact Margaret Royle:



0207 972 1240



margaret.royle@dh.gsi.gov.uk

North West Regional Family Forum



This Forum meets for families at least four times a year and the venue swaps around to make it fair for everyone. From this Forum, eight family carer reps attend the Regional Task Force.

Julia Erskine is a member of the Forum and regional Task Force and is now the rep for the National Family Carer Links Group.



Julia says: *“Being so local and on the ground, and then having the regional board to take good and not so good practice to makes a real difference to how well I feel listened to and valued. Now to be able to link in nationally makes a huge difference because family carers are really getting their voice heard at every level.”*

To find out more or join the mailing list, contact Julia:



07951 792941



Julia@policymaking.fsnet.co.uk

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South West Regional Family Carer Network



There is currently no coordinated South West Family Carer Network at the moment for a variety of reasons, not least the huge geography of our area – but this is set to change very soon. The South West Valuing Support Team is going to employ someone to coordinate a regional Network for Family Carers. For more information contact Carol Robinson on carol.robinson@southglos.gov.uk or 01278 432002



In the meantime, Rachel Mason, (a family carer who is also employed to support other families in Somerset), is representing the South West on the National Links group and would love to hear from more family carers in the region. You can contact Rachel on:



07919 165162



rachel.k.mason@homecall.co.uk

East Midlands Regional Family Carer Network

This Network is organised by the Regional Valuing People Support Team. It meets four times a year at different venues around the East Midlands.



Michael Ormian attends on behalf of Lincolnshire Partnership Board and is also the regional rep for the National Family Carer Links Group. He says: *“It’s very valuable to know that issues and problems we experience in our local area are often echoed in other parts of the region, and it’s great to discover how these other areas come up with innovative solutions”*.

To find out more or join the mailing list contact: Carol Peacock on



01623 812933



carol.peacock@eastmidlands.csip.nhs.uk

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HFT's Family Carer Support Service



HFT (Home Farm Trust's) Family Carer Support Service (FCSS) was set up 13 years ago. The FCSS supports family carers so they, and their relatives with learning disabilities, can live full, well-supported lives, as described in Valuing People. We work at individual, local and national levels to help make this happen.



We think family members are experts at supporting their relatives, creating person centred opportunities and speaking up for them to have fulfilling lives. But, quite often they do not know their rights and they have difficulties finding information. They can also feel they are not valued by people who work in services. We aim to help family carers with these difficulties.

The Family Carer Support Service:



- We help **family carers** from all over the country get information and support on the phone, by email and letter
- Every year we run 4 series of **workshops for groups of family carers** to make sure they are familiar with the *Valuing People* agenda and how this is happening in their area
- We keep a **Family Carer Database** of individual family carers and organisations who have asked for our mailings



- We write and send out **Family Carer News Digests**, invitations and details of workshops twice a year
- We produce a **Holiday Information guide** every year



- We have made ***Getting in control***, a DVD about individualised funding for family carers and others.

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- We **work with other organisations** so that more people understand what family carers do and the best ways of working with them. This includes:
 - o Setting up and managing the **National Family Carer Network** for its first 3 years (2004 – 2007)
 - o Completing action research about **Transitions** with the Norah Fry Research Centre (NFRC)
 - o Working in **Russia** to help develop family support services and inclusive education for disabled children
 - o Working with other organisations to publish a **Trainer Pack** to help more staff work really well with the families of the people they support.



If you want to find out more about anything above, contact by:



0117 930 2608



familycarersupport@hft.org.uk
www.hft.org.uk/carersupport



Family Carer Support Service, HFT, Merchants House, Wapping Road, Bristol BS1 4RW

HFT can offer lots of different ways of supporting families.

Reaching Out

MENCAP
Understanding learning disability

'Reaching Out' highlights the double-discrimination families from black and minority ethnic (BME) communities face when seeking services for their family members with a learning disability.



To find out more about the 'Reaching Out' research project, and the work that Mencap is currently doing for BME communities, go to www.mencap.org.uk

Mencap is working hard to support families from different communities

Recognising Fathers



Recognising Fathers aims to find more about the experiences of fathers of children with a learning disability because fathers are often ignored by workers in services.

The information is being used to find out how policy and practice can be changed to improve support for fathers and families. The report and a summary from this work are available at www.learningdisabilities.org.uk.



We are now carrying out a national survey of fathers with a child aged 19 or under. If you are interested in completing a questionnaire or could circulate information, get in touch with Christine Towers:



020 7803 1158



ctowers@fpld.org.uk

Work is happening to make sure fathers who are carers get the right information and support

Breaking Point

MENCAP
Understanding learning disability



Mencap launched the Breaking Point campaign for more short breaks for families in 2003. From May to July 2006, we followed up our work with a survey of 353 families in 6 local authority areas in England and Northern Ireland. We found many shocking stories of families still being denied the right to a family life because of a continuing lack of short breaks.

Your Breaking Point Guide – campaigning for more and better short breaks can help you campaign for more and better short breaks. Download from www.mencap.org.uk/breakingpoint

For more information, ring the Breaking Point team:



020 7696 6952



breakingpoint@mencap.org.uk

Mencap has a pack to help carers ask for more breaks

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Launching the guide to Short Breaks



Families tell us that having a break can really make a difference for everyone in the family. On behalf of the Valuing People Support Team, Paradigm have put together a guide for Partnership Boards about the range of short breaks that families value.

To get a copy of the guide, please visit the Valuing People website at www.valuingpeople.gov.uk or call Mita Shah on 07917 594017

Partnership Boards can get a copy of a guide to short breaks

Local Involvement Networks (LINKs)



'Our health, our care, our say' said that people should have 'more choice and a louder voice'. It said local communities should have more say in the way the whole health and social care system is designed and works.

Ideas about how to do this were published in a report called 'A Stronger Local Voice'. It says there will be new organisations called **Local Involvement Networks (LINKs)**. LINKs will replace Patient Forums.



The rules about LINKs and how they will work are part of the **Local Government and Public Involvement in Health Bill**. Parliament is looking at this now. Patient Forums should stop in March 2008 and LINKs to start from April 2008.

For more information:



Department of Health www.dh.gov.uk

National Centre for Involvement www.nhscentreforinvolvement.nhs.uk

LINKs is a new way of making sure local people can speak up about the health and support where they live.

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National Family Carer Network

We are coming to the end of our money from the Department of Health Section 64 grant and thinking of what we have done so far and what is planned for the future.



Over the last year we have continued to build our relationships with groups and organisations at a national level. We have been part of national working groups like:

- 'What to do about abuse'
- 'Common Assessment Framework for Long Term Conditions'
- Health Care Commissions Audit of Learning Disability Services
- Welfare Reform

Other things we've done include:

- Organising events on In Control and the Mental Capacity Act
- Working with the National Family Carer Links Network
- Improving our website (ready in September)
- Producing information sheets for family carers
- Starting to evaluate how useful the Network has been so far



The Network has enough funding to keep going until August 2008. This is thanks to support from the Valuing People Support Team and other major organisations.



The Network is becoming a registered charity in its own right. This process is taking a lot of time, energy, and commitment but becoming an independent charity should offer real opportunities for the network to get stronger.

For more information about the Network, contact Helen Dorr:



07747 460727



helen.dorr@hft.org.uk

www.familycarers.org.uk

The National Family Carer Network is going to be a charity. It will keep on giving a national voice to family carers.

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Representing Family Carers on the Independent Living Review - by Jean Willson



Last August, I became a member of the Expert Panel for the Independent Living Review (ILR) for Disabled People on behalf of family carers of people with learning disabilities.

The Review was launched in July 2006 to find creative and practical ways to support independent living for disabled people. The review takes a whole life approach, from young people in transition to adulthood and including older people.



The review is a cross-government project led by the Office for Disability Issues (ODI) and will take 12 months. To find out more go to www.officefordisability.gov.independent

The ODI set up an Expert Panel to shape and steer the work of the ILR project team. The panel uses real life case studies based to work out solutions to problems.



We also discuss ideas from the project team; feeding in information and good practice examples from around the country. Family carers have written in with good practice or things they'd like to change. They have also been part of workshops and regional events.



The ODI would be very pleased to receive your comments:
Independent-living-review@dwp.gsi.gov.uk



Independent Living Review Project Team, Office for Disability Issues,
The Adelphi, 1-11 John Adam Street, London WC2N 1 HT

Family carers are part of work to improve the way disabled people are supported to live more independently.

Supporting Carers With a Learning Disability



More people with learning disabilities are becoming carers. Lots of people are looking after their parents who are getting older and need help. Others are looking after husbands, wives, partners or friends.



Things people do as carers can be anything from helping someone to wash, dress and take their medicine to helping with shopping and being good company to stop people from feeling lonely or scared.

If people with learning disabilities were not caring then often the person they look after would not be able to stay at home either.



It is difficult for most carers to get the right information, support, breaks and help. If you are a carer with a learning disability, it can be even more difficult.



Many people don't recognise that people with learning disabilities can be carers too. Lots of work has started to help make sure that carers with learning disabilities get recognised and supported.

People with learning disabilities can be carers too. They need the right help and support

Carers Assessments

A good carers assessment can help workers understand what people are doing to help out and what support they need.



The Valuing People Support Team are writing an easy read copy of their guide to help carers get good carers assessments.

A guide is being written to help carers with learning disabilities get the right help and support

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Who cares for us?



Eve Rank and Richard West have started the *Who cares for us?* campaign to make sure carers with a learning disability are not forgotten.

Eve and Richard have been working hard to make sure that more people recognise that people with learning disabilities can be carers too and that they get the right help and support.



They have spoken with the Minister, Ivan Lewis and at lots of conferences. They have also been to Parliament to talk to MPs and make sure they don't forget carers with a learning disability.

They are very busy and Community Care magazine has just written a big article about their campaign.



Who cares for us? is being supported by Inspired Services. You can read more about Eve, Richard and their campaign at www.inspiredservices.org.uk

Eve and Richard are making sure people understand that people with learning disabilities can be carers too.

Network for Carers with Learning Disabilities



The Valuing People Support Team runs 4 meetings a year to bring people together to talk about the work that is happening to support carers with learning disabilities.

To find out more contact Carol Peacock on



01623 812933



carol.peacock@eastmidlands.csip.nhs.uk

There are national meetings to link up work to support carers with learning disabilities

Mutual Caring Project

Many people with learning disabilities living in older families find themselves doing lots more to help out. Often the older person and the person with a learning disability are looking after each other. They make great teams but things can also be a real struggle. This is known as 'mutual caring'.



The Foundation for People with Learning Disabilities has a small new project called the **Mutual Caring Project**. The project is working with 4 places who are testing out ways older families get support when mutual caring is happening.



Each pilot site is finding at least 5 older families and helping them to get the help they need now, and to plan for emergencies and the future. When the project finishes it will have at least 20 stories about what works and what needs to be improved to support these older families.



Each place is also looking at ways local services can join up better to support older families where mutual caring is happening. There are usually lots of really good services around that can help but often older families don't know about them.

The project has not been going very long but the pilot sites are in Norfolk, Leeds, Shropshire and Barnsley. There are also Network meetings for other people who are interested in making things better for older families who are looking after each other.

To join the mailing list or find out more, contact Dalia Magrill:



07863 341475



dalia@blueyonder.co.uk

There is a new project to find out how older families can get better help when they are all looking after each other

Keith's Story



Keith and Paul.
Photograph by Terry
Speake © 2007

“My parents look after my brother and me but because they are getting older and they have both been ill they can no longer lift Paul. Because of that, I do all the lifting. Fortunately Paul is not heavy.

I also help to keep Paul's face clean as he coughs a lot. We all help to keep Paul safe

Because we all help each other, Paul can live a good life at home.”

Keith helps his parents to care for his brother, Paul.

A final message from Cally Ward....

Finally, a big thank you to Lynne Elwell, Molly Mattingly, Christine Burke and Ali Mohamed for the work they have done for the Valuing People Support Team on supporting family leadership now that their secondments have ended.

Also, congratulations to Lynne Elwell who has a new job working with In Control. Lynne will be helping us to put together the next family newsletter later in the year on this topic.

LATE NEWS: The National Family Carer Network is applying to become a charity. Later this summer the Network will be advertising for a new Coordinator to take its work forward. If you or anyone you know might be interested in the position, please contact Robina Mallett on 0117 9302608 or email her at robina.mallett@hft.org.uk

This newsletter was edited by Cally Ward and Dalia Magrill. There is never enough space to put in everything that is sent to us so we apologise to those people who sent things in that we have not been able to include this time.

