

Health Newsletter

Autumn 2007

Valuing People
Support Team

This newsletter is about some of the important things happening about the health of people with learning disabilities and about health services

Greetings from Debra Moore

Hello

This newsletter is about important things to know about in relation to better health for people with learning disabilities. You may be aware that there have been a number of reports about the serious problems people with learning disabilities and their families have experienced when using the different parts of the NHS. This newsletter has information about these issues and other work that is happening as well as some examples of good practice.

This includes:

- The Independent Inquiry that was launched following the publication of the Mencap Report ***Death By Indifference***.
- The audit of specialist learning disability health services that was undertaken by the Healthcare Commission in response to their investigations in Cornwall and in Sutton and Merton Primary Care Trust.
- The new Primary Healthcare Service Framework and health checks for people with learning disabilities.
- Information about people who have more complex needs, including people who get into trouble with the law.
- Some examples of good practice, including the positive progress being made in Cornwall.
- Information about new and forthcoming guidance.



Debra Moore

**Joint programme Lead and Health Lead
Valuing People Support Team**

Valuing People Next Steps: update from Rob Greig



As you know, work is taking place to 'refresh' ***Valuing People***. This means setting new focus and direction for the next few years. We expect people's health to be an important part of this work. It is too early to say in detail what will be included about improving health. However, some important things will be part of the work:

- introducing health checks for everyone
- making sure that primary care and acute hospitals serve people better
- making sure that specialist learning disability services are in line with good practice.

These things were part of ***Valuing People*** from the start. The most important challenge is how we make sure they happen everywhere, rather than just in some parts of the country. We expect to publish the next stage of the work very soon.

Valuing People is being looked at again. Better health and better health care should be part of this.

THE GOVERNMENT'S
LEARNING DISABILITY
TASK FORCE


The 4th Annual Report from the Learning Disability Task Force can be found at:



<http://nationaldirectorld.org.uk/dynamic/ond24.jsp>

Department of Health response to *Equal Treatment*

The Department of Health wrote a 'Promoting Equality' plan to help people with learning disabilities get good primary health care. Some good things are happening:

-  Advice for Primary Care Trusts about commissioning primary care <http://www.primarycarecontracting.nhs.uk/204.php> (see page 4).
- This autumn the Valuing People Support Team will share advice about doing health checks.
- The Equalities and Human Rights team is writing Good Practice Guidance to the NHS about the Disability Equality Duty, with the Valuing People Support Team.
- Guidance will also come out soon on commissioning health services that are just for people with learning disabilities (see page 6).

More needs to happen on other things the Department said it would do, like:



- making sure self-advocacy training includes mental capacity
- having a say on staff training
- work in the 'Health Inequalities Task Force', led by the National Director for Primary Care, David Colin-Thomé. The NHS Institute will include the health of people with learning disabilities in a 'rapid learning' event.

The Department will go on with its plan. It will work with the new Commission for Equalities and Human Rights, which took over from the Disability Rights Commission on 1st October.

The Department of Health wrote a plan about better health care. Some things are happening now. The work will carry on.

Independent Inquiry into Access to Healthcare for People with Learning Disabilities



The Secretary of State for Health announced this Inquiry to look at the action needed to ensure adults and children get good general health care in England. This means acute medical (hospital) care and general primary care, not mental health services or specialist learning disability services. The Inquiry will also learn lessons from the six cases in Mencap's report ***Death by Indifference***. (The Health Service Ombudsman is investigating these cases and the Inquiry will look at what she finds out).

The Inquiry is chaired by Sir Jonathan Michael. The team consists of experts on health and social care services and people with learning disabilities who have experience of using services. Two special groups will be held to listen to family carers and those who support people with high individual support needs.

The Inquiry collects information from people with learning disabilities, families and staff, in particularly how things could be improved and examples of services working well. All information given to the Inquiry will be kept private. The Inquiry has a website at www.iahpld.org.uk which gives more information about the process.

You can read ***Death by Indifference*** at



www.mencap.org.uk/html/campaigns/deathbyindifference/reports.asp

A big Inquiry is looking at how to make sure people get good general health care. You can tell them what you think.

Healthcare Commission review of in-patient health services for people with learning disabilities



The national audit (review) is nearly finished. Over 300 people were trained. They did 155 visits to NHS learning disability services and independent health services. Each organisation is checking the report done on its visit. Some are already doing action plans.

The national report and a DVD will come out at the end of November. We hope there will be a national event to launch the report. People with learning difficulties and family carers who were part of the process will share their experiences.

Fiona Ritchie is leading the audit work. She will write about the main results in the next newsletter.

The Healthcare Commission has looked at health services that are just for people with learning disabilities. The report will come out in November.

Advice for Primary Care

The Primary Care Service Framework explains to family doctors (GPs) and their teams how important it is for them to carry out health checks for people with learning disabilities every year.

Primary Care Trusts and GPs who pay for health services (Practice Based Commissioners) need help to understand what sort of health services people with learning disabilities need. That is why a new paper has been written to help them:

- decide what medical services should be there for everyone
- know how to buy (commission) these services
- understand how these services will help people with learning disabilities.

During the health check every year the GP should check the person all over and look at:

- family history and health risks
- immunisation (protection against some diseases)
- health screening (like breast screening)
- health promotion (like healthy eating)
- sight and hearing
- long term illnesses like epilepsy
- sexual health
- drug and alcohol use
- continence (managing going to the toilet)
- behaviour problems
- fitness, mobility and posture
- mental health and emotional needs
- health problems particular to that person
- medication
- oral health
- family carer details
- referrals made and subsequent follow up
- risks identified and actions to be taken



Valuing People SUPPORT TEAM *Newsletter* Health

The paper ***Primary Care Service Framework: Management of health for people with learning disabilities in primary care*** was written by Jeff Anderson at Primary Care Unlimited on behalf of the Department of Health and NHS Primary Care Contracting.

There is also some other advice for GPs and learning disability nurses to help them do their jobs. These papers were written by Primary Care Unlimited and the Foundation for People with Learning Disabilities.



You can find out more at

www.primarycarecontracting.nhs.uk/204.php

Valuing People Support Team are also holding a series of events to tell people about the framework, including health checks and other related health initiatives. For more information on these contact



Debra.Moore@dh.gsi.gov.uk or

Kirsty.Hannam@dh.gsi.gov.uk

It is important for GPs and their teams to get support so they can offer health checks for people with learning disabilities each year.

Health checks in Birmingham



Community Learning Disability Nurses in Birmingham are helping people to get good health care by working with services like GPs, nurses, dentists, opticians and hospitals. Some things that help are:

- Easy read letters and leaflets
- Training and help to think about good health
- Services working together
- Supporting people to know their rights
- Looking at how people consent (say yes or no) to treatment
- A book people can take to hospital
- A checklist about learning disability
- Support pack for GPs and their teams
- Lists of people (registers) so they can get the right support.

People who do this are called 'health facilitators'. There are 6 in Birmingham. Another 2 are working on better services for eyesight and hearing. All 542 GPs in Birmingham have a computer form to help them do health checks every year for people with learning disabilities – the right check for each person.



How have health facilitators helped?

- 31 people supported to register with a GP
- More than 8,000 people listed with GP Practices
- More than 1,500 health checks completed
- 472 health action plans completed
- 205 training sessions and support to residential homes
- 97 people helped to have an eye test
- 22 people helped to receive eye treatment or surgery
- 42 people with difficult health problems helped in hospital and getting the right support to leave hospital
- 647 contacts with people while in hospitals
- 205 health problems found during health checks that were not known about before

What do people say about help from health facilitators?

'The health facilitator helped me to get my blood test done. I don't like needles very much but the doctor came to my house to do it so I didn't get so worried'

'I had a plan made for me about how to stay healthy because I have diabetes. The health facilitator arranged for me to go to the weight clinic to see if I had lost weight'

'I have to take my temperature every day. The nurse made me a chart. I have to go straight to the hospital if it goes up because I have cancer. I know what to do.'

'I had some training on smears. I went and had it done. It wasn't too bad.'

'My toenails were really long. I couldn't walk properly. The facilitator told a man to come and cut my nails so that I didn't fall over any more.'

For further information please contact Susan Brady on telephone number



0121 465 8400



or email susan.brady@sbpct.nhs.uk

Learning disability nurses in Birmingham are helping people get better health care

Commissioning health services that are specially for adults with learning disabilities

The Department of Health will publish good practice guidance soon about commissioning health services that are specially for adults with learning disabilities. 'Commissioning' means deciding what services are needed and paying for services.

This guidance will respond to growing concern that in some areas money is not being used in the best ways and services are outdated. This can mean some people end up 'stuck' in health service units for a long time, sometimes many miles away from home. Some people may have difficulty getting their health needs met. Some people may be at increased risk of neglect or, at worst, abuse.

The guidance is to help people design services that will support ordinary health services to do a good job. It will also help them to design services that directly serve people with the most complex needs.

Lots of people and organisations have contributed to writing the guidance. When it is published there will be chances for people to come together and think about what it says.

New guidance is coming out about health services that are just for people with learning disabilities.

'Do Once and Share' project on health action planning

The 5 Boroughs Partnership NHS Trust agreed to develop a 'care pathway' and documents linked to it. A 'care pathway' is a kind of chart, showing what different services should do and how they all link together. The work was done as part of a bigger 'Do Once and Share' programme run by part of the NHS called Connecting for Health. The idea of 'Do Once and Share' is that someone works out how to do a job well and then tells other people so they don't have to work it out for themselves.



This pathway shows people best practice in doing health action planning for adults with learning disabilities. The aim of the project was to produce guidance that was general enough to work anywhere in the country. Alongside the pathway is a guide that people could use to adapt the process locally and make it work in their area.

To see the pathway and the linked documents, contact



doas.programmeoffice@nhs.net

There is advice on how to do health action planning.

Young people who have lots of health problems

More and more young disabled people have lots of difficult, long term health problems. Some of them need the support of medical equipment like a feeding tube into the stomach (gastrostomy), a breathing tube in the neck (tracheostomy) or a machine to help them breathe (ventilator). Parents are doing highly technical care for their sons and daughters.



Research shows that services have not met the particular support needs of this 'new' group of disabled young people. Parents say they find it difficult to get flexible and personalised support that helps them care and helps their child to have an independent social life. Parents say it is difficult and stressful trying to get special equipment and medication. Parents sometimes feel that professionals don't recognise parents as experts and don't notice how hard it can feel for parents to do all the care for their child.

These young people are growing up and starting to use services for adults. Research shows that young people and parents are unhappy that they don't get enough information about this change. They don't get good plans for 'transition'. Parents feel they don't have enough information on future choices for their children. Some feel they are being pushed towards residential care. Others are worried that complicated supports may not get moved over with their child to adult services. Some young people are getting services that don't exist in adult services.



Many of the difficulties that families face are because services don't work together. This might be not working with parents and young people or it might be not working with each other. Services need to work together to plan, pay for and provide support. We have to do early planning together, with young people and families.

For more information, contact Dr. Susan Kirk



sue.kirk@manchester.ac.uk

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Health

Valuing People Support Team will make sure more people understand the needs of these young people. We will help people to design high quality support that helps young people be included. We are planning a series of events for Spring 2008.

For more information on these contact



Debra.Moore@dh.gsi.gov.uk or

jcobb@fpld.org.uk

Some young people have lots of difficult health problems. Sometimes their health problems are very complicated. Services need to get better at supporting them and their families.

‘Challenging behaviour – a unified approach’

People from the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists wrote this report together.



We want to improve the quality of work by people whose job is to support people with learning disabilities who show behaviour that other people find difficult. This includes professionals like psychiatrists, psychologists and speech and language therapists. The report brings together the ways these different professionals work in understanding and trying to manage challenging behaviour.

The report also says very strongly that people should use the words “challenging behaviour” very carefully. They should not use them as if they were describing a disease or something wrong with the person. The words mean that people who care for and support the person with learning disabilities have to find better ways of understanding why they behave like they do. They have to find ways of supporting the person that mean the person does not have to behave that way or that carers can cope with the behaviour better and for longer.

People with learning disabilities who behave in a challenging way are often not listened to and not allowed to join in the things that everybody else does. This report wants to encourage professionals and carers to do all that they can to improve the quality of life of these people and to provide better services where they live.

The report talks most about adults with moderate to severe learning disabilities. Children and other people with less severe learning disabilities could also be included.



This report tries to:

- Give a newer and better explanation of challenging behaviour.
- Bring together what people know about how to understand and work with challenging behaviour.
- Explain how professionals and staff from different services can all work together.
- Help people find better and more imaginative ways of supporting people whose behaviour is challenging.
- Teach and help the people who develop and pay for services.
- Help people who use services and their family carers and staff.
- Give some standards of good practice for people to compare their services with.
- Encourage people to build better and more joined-up services in the places where people live, so that fewer people get sent to services a long way from home.
- Give ideas about how professionals and paid support staff and family carers can be better trained.
- Help people think about what more they need to know and find out about challenging behaviour in the future.

We hope that this report will go together with other reports that people are writing on challenging behaviour. This will help there to be better and more joined up ways of working with people whose behaviour is challenging. The report should be interesting to many different sorts of health and social care professionals, family carers, staff, service providers and commissioners.

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The report can be downloaded free:



<http://www.rcpsych.ac.uk/files/pdfversion/cr144.pdf>

For further information contact:

Dr Roger Banks, Vice President, Royal College of Psychiatrists



rbanks@rcpsych.ac.uk

Dr Alick Bush, Chair of Faculty of Learning Disability,
British Psychological Society



Alick.Bush@SCT.NHS.UK

There is a new report about how to support people with learning disabilities who show behaviour that other people find difficult.

'No One Knows' about prisoners

Some people in prison have learning difficulties. The Prison Reform Trust is working on a new project to find out how people with learning difficulties are treated when they get into trouble with the police and are sent to prison. The project is called **No One Knows**.

The project is supported by a group of people with learning difficulties, the Working for Justice Group. Members of the Group talked about their own experiences. They told the project what questions to ask.

Group members said it is important to be able to see a doctor and have your medicines. Members understand that medicines may be taken away for safety, but you should have them if you need them. One member, who has asthma, had his inhaler taken off him at the police station before he was locked up despite asking to keep it. He also has epilepsy and felt that his request to see a doctor was not taken seriously:

In May three members of the Working for Justice Group spoke at a meeting in the Houses of Parliament. They told Members of Parliament what they thought should change, like training for prison staff to help them support people with learning difficulties when they are in prison. After the meeting one of the group members said:



"I never dreamed that I would be there and getting to speak and people listening."

The No One Knows project will last until 2008. At the end of the project we will write a report. The report will be about what people have told us about their experiences.

The report will tell the government what they should do to make things better for people with learning difficulties who get into trouble with the police.

The Prison Reform Trust is a registered charity working to help people who are in prison.

To find out more about No One Knows contact



jenny.talbot@prisonreformtrust.org.uk

or visit the website:



www.prisonreformtrust.org.uk/nok

No One Knows is a new project about how people with learning difficulties get treated if they get into trouble with the police and are sent to prison

Positive practice with offenders

A booklet came out in February from a project on work with people with learning disabilities who get into trouble with the police (offenders). It is called Positive Practice, Positive Outcomes – ***A Handbook for Professionals in the Criminal Justice System Working with Offenders with Learning Disabilities.***

This is about:

- recognising when a person has a learning disability
- communication and support needs of disabled offenders
- the law and what they must do to protect disabled offenders
- links with local learning disability services.

The people it was written for think it is helpful. A training pack is being written as well. The Department of Health paid for the project.

<http://www.kc.csip.org.uk/viewresource.php?action=viewdocument&doc=98519&grp=1>

There is a good practice booklet about working with offenders with learning disabilities.

The 'Tough Times' project

The project was about people 'stuck' in secure care, sometimes a long way from home. 'Secure care' means services with locked doors and high fences to stop people getting out.

The project looked at why people get stuck in secure care. We looked at services that helped people to return home or stopped them going into secure care. We held 3 conferences about working together better to create local services to meet local needs. We wrote ***Chicken Soup for***

Learning Disabled Offenders and ***the Dream-catcher of Partnerships***. We made 6 recommendations to bring people back closer to home safely. We helped local people to think about how they could use our ideas.



You can find Learning Sheets at:



<http://www.ndt.org.uk/projectsN/TTFactS.htm>

or contact Wendy Silberman, who was the project manager



wendy.silberman@ntlworld.com

This was a 3 year project paid for by the Department of Health.

The Tough Times Project looked at better local services for people who can be hard to support.

Making change happen in Cornwall

by Carol Tozer, Director of Adult Social Care, Cornwall County Council

Last year's report on abuse in Cornwall report was a turning point – nationally and locally. Its catalogue of abuse within Cornwall Partnership NHS Trust revealed system-wide failures across health and social care. What happened to the people “served” by the Trust is a matter of profound personal and professional shame for me and my colleagues. The horror of what was found was fed back by the investigation team in the form of adult protection referrals to the Department of Adult Social Care, while the investigation was still going on.

My chief executive colleagues in the NHS and I made a promise then. We vowed that our response would ensure that Cornwall's support for people with learning disabilities and their families would not “catch up” with elsewhere, but rather “leapfrog” to providing some of the best support on offer anywhere. And we were crystal clear that this transformation would be led by the interests and preferences of people with learning disabilities and their families. I only have space here to inform you about two “leapfrogs” we have done: housing and support.

Housing

One of our key tasks was to move people out of the Trust's “Treatment and Assessment Centres” into their own homes. We have not finished this yet. It involves a massive exercise to find homes. We have been supported brilliantly by Golden Lane Housing. The people concerned, their families and advocates have relished the house-hunting.

By 1st January 2007, everyone from Budock Hospital had moved into their own home. By October this year, we expect everyone living in the Trust's Treatment and Assessment Centres to have chosen their own homes. By the end of March 2008, people living in 9 of the Trust's Supported Living Services houses will also have chosen new care and support providers.

Of all these people, up to 30 will have a shared equity mortgage in place. By the time we have finished, we believe that there will be more people with learning disabilities owning their own homes in Cornwall than many other places.



Support

People with learning disabilities, their families and advocates have also led the processes we have used to bring new service providers into Cornwall (commissioning and procurement). The Leadership Group for learning disabilities (people with learning disabilities, family carers, commissioners and senior managers) agreed a framework for the values, standards and expertise we needed from these new providers. The Joint Commissioning Group (which also includes people with learning disabilities and carers) then set these out into Service Level Frameworks, with a range of prices.



Then we went out to tender and all providers who passed the tests in the Service Level Frameworks were invited to a series of “Care Fairs”. Over 300 people with learning disabilities, family members and carers attended these fairs. They made judgements about each of the providers based upon presentations and personal discussions. These evaluations went back into the Joint Commissioning Group. The successful organisations became “approved providers”.

Next, we held a series of house meetings with the people living in the Trust’s establishments, their families and advocates, so each and every individual could choose their own provider. This part of the process has been especially detailed. The people concerned and their families want to make the right choice for themselves. It has needed many hours of discussion about what was good or bad about each organisation before some people have felt able to make that decision. Finally, the people concerned have then worked with their provider to agree the what, where, when, how and who of the support they receive.



People in control

Both these examples of change have given rights of citizenship to people previously denied them. Both examples have placed people with learning disabilities and their families in control. Both examples have taken time but will – we hope – result in lifelong fulfilment and achievement.

Better services for children

The Partnership Board and the Primary Care Trust supported the Parent Carer Council to ask parents and carers of children with learning disabilities about short breaks services. They said the most important things were:

- The quality of staff
- More daytime breaks, particularly during school holidays
- Individual plans for support, based on good information.



You can get the report from Leah Parker, tel. 01726 627954.

The Parent Carer Council has done a report about short break services for children in Cornwall.

Good changes in hospitals

The Royal Cornwall Hospitals Trust and the Primary Care Trust are working with people with learning disabilities, families and carers to improve care in hospitals. They looked at the problems people can have when they go to hospital. The Hospitals Trust agreed a plan about changes. People with learning disabilities will be involved in all the changes. Work so far includes:



- A 'Hospital Liaison Nurse' post
- People to take a lead in each hospital department
- Training for hospital staff, using 'e-learning' on computers. People with learning disabilities and parents shared their experiences, helping hospital staff to understand their needs. People with learning disabilities will also help with other types of training

The Hospital Checkers are a group of people with learning disabilities. During the summer they visited two hospital sites. They wanted to check hospital services to find out what was good or bad about signs, information, food and infection control (like washing hands). The visits were recorded. They will tell the Hospitals Trust what they find. They plan to go on helping to improve hospital services across Cornwall.



You can get the hospital plan from Sandra Arnold, tel. 01872 252264

Hospitals in Cornwall are working hard to give better care to people with learning disabilities. The Hospital Checkers group are doing checks to see how things are going.

Good changes in primary care

Links with primary care services (GPs and their teams) are very important for getting better health. The Primary Care Trust gave jobs to 4 'primary care liaison' nurses to make sure people with learning disabilities have good access to primary health care services.

The new nurses will work closely with people with learning disabilities, family carers and staff working in community hospitals, primary care services and Cornwall Partnership Trust. The nurses will help to start 'health checks'. They will give staff training to be aware of what people with learning disabilities need.



New nurse jobs in Cornwall are helping to get better health care for people with learning disabilities.

‘Let’s All Plan For Health’ Training Team

The ‘Let’s All Plan for Health’ group made an accessible training programme on ‘health action planning’. The group is planning for people with learning disabilities to get jobs as ‘health trainers’. This is being done by people working together from the Get Real Team, People First, the Respect Group, learning disability nurses and speech and language therapists.

The ‘Let’s All Plan for health’ team talked to lots of people to help them draw up the training programme. They met self advocates, family carers and health professionals. They looked at good practice examples from Surrey Partnership NHS Trust and Barnet Primary Care Trust. The group looked at what should be in a health action plan. They decided on a form. This was tried out with a GP surgery in Caradon District Area.



The group developed new ways of doing training on good health and health action planning. A speech and language therapist in the team helped by providing pictures, symbols and easy words for the training pack. The training has been tried out. It is being offered across Cornwall from 3rd October 2007.

This training is paid for by a small amount of money from the Cornwall Partnership Board. It is checked by the Partnership Board’s ‘Big Health Group’.



Contact Gavin Thistlethwaite at Cornwall and Isles of Scilly Primary Care Trust on 01726 627996

The ‘Let’s All Plan for Health’ team is doing training about health and health action planning.

Postural care - a rough guide to protecting body shape

Postural care is all about protecting body shape during the day and night for people who have movement difficulties. This helps to avoid some health problems.

There are 8,760 hours in a year. Someone with movement problems might spend about:

1,140 hours in school or day services

3,640 hours in bed

7,620 hours with their family.



It is really important to help families to understand how body shape can change if a person is left in a bad position, particularly at night.



For further information check out www.posturalcareskills.com



For a copy of 'I Got Life – A Person Led Postural Care Pathway' go to <http://www.library.nhs.uk/>

and click on to

<http://www.library.nhs.uk/learningdisabilities/viewResource.aspx?resID=268997>



or contact me directly at Sarahhill@posturalcareskills.com

To find out more or get in touch with other people interested in this subject, join the free UK Postural Care Network by emailing your name, job and area to



Network@posturalcareskills.com

A person with movement difficulties can be helped to stay healthy by looking after the shape of their body. This is called postural care.

Assessing pain in severely disabled children

Many people with severe learning disabilities cannot tell us in words about pain. We have to notice other ways of communicating. The Paediatric Pain Profile (PPP) is a tool for assessing pain in severely disabled children. The PPP lists 20 behaviours that parents and professionals said helped them to 'know' when children had pain. Each behaviour gets a score to show how often it happens. We looked at whether the score can show the difference between pain and a 'good' day. We looked at whether the score goes down when the child has treatment for pain.



We are supporting some nurses to use the PPP with parents of severely disabled children. We will find out how the tool is used. We will ask parents if it was useful.

We have not tried the PPP with adults, but some people are using it. We would like to find out whether the tool is helpful for adults.



We have a website www.pppprofile.org.uk .

We have written some papers about our work.



Contact Anne Hunt ahunt@uclan.ac.uk



Tel. 01772 895148

It can be hard to know when very disabled children are in pain. The PPP is a new tool to help with this.

Eyesight and hearing

Lots of people don't know that they have sight or hearing problems. There are ways to help people see and hear better.



Eyesight changes as you get older. You should have your eyes tested regularly. Opticians check your eyes are healthy. Most people with learning disabilities get a free eye test.

Eye tests can feel strange. It's a good idea to take someone with you. You can visit before the test and look at the equipment. The optician will say if you need glasses. People take time to get used to wearing glasses. Some people might need an operation.

Graham can cope with money now he can see the coins properly. That's what got him wearing his glasses.

The optician said Janet had an eye infection. That's why she kept rubbing her eyes. Her Mum put eye drops in every day and her eyes got better.

You should tell a doctor or nurse if you can't hear well. They will check your ears. Some people have too much wax in their ears. It stops them hearing clearly. The wax might need to be taken out.

A hearing test can show if you have hearing impairment. There are different types of tests. People need support to get a test. Some people need a hearing aid. People take time to get used to wearing a hearing aid, but they can really help.

It was lovely. They got all the wax out of my ears and I could hear people again. My Mum and I couldn't stop talking. It was a long time since I heard so well.

There are many ways to help people with sight or hearing problems. People's quality of life can be much better when they can see and hear more.



Gill Levy g.levy@lookupinfo.org



tel. 020 8348 3533



Website: www.lookupinfo.org

Encouraging positive mental health

Everybody has mental health needs. When these needs are not met we are at risk of developing mental health problems. But there are a number of things that can help to keep us mentally well. These are called 'protective factors'. They include:

- Having someone to share your worries with
- Being physically well
- Speaking up for yourself
- Being valued.

Two groups of people with learning disabilities have been working together to think about mental health. They are:

- Beat the Blues Group in Greenwich
- The Tuesday Group in Lewisham.

The groups meet regularly and talk about what can help them stay well. Some things they have worked on are:

- Being assertive and knowing your rights
- Recognising stress and dealing with it
- Eating a healthy diet
- Feeling safe at home and in the community.



The Tuesday Group, Lewisham

Valuing People SUPPORT TEAM *Newsletter*

Health

The groups have been helping to draw up a training pack. This will teach people with learning disabilities about their mental health. The pack includes some videos. The videos show group members talking about:

- What does mental health mean to people with learning disabilities?
- What things can help you stay mentally well?
- What things can make you depressed or anxious?
- What can you do to help yourself when you are depressed or anxious?
- What services are available?
- How should professionals work together with people using services?



Group members have also helped to make accessible leaflets about mental health problems, treatments, professionals and services. We hope that the training pack will be available early in 2008.



For more information call Steve Hardy on 020 3228 9740



or email steven.hardy@kcl.ac.uk

It is important to look after your mental health. Two groups have been working on information about mental health.

‘Green Light for Mental Health – Making It Happen’ An update on what is happening

The ‘Making It Happen’ national programme is starting to make a difference for people with learning disabilities using mental health services. Each area that is taking part in the programme has agreed some actions.

One of the most powerful parts of the programme has been hearing from people who have used services and family carers about the changes they would like to see. For example:



- Plymouth: people with learning disabilities are helping us to think about performance indicators (what good services should look like) that we hope will be used across England.
- Doncaster: regular days for people with learning disabilities and mental health problems to meet with senior managers, staff and commissioners to make sure that their voices are heard and plans reflect their views.
- Southampton: the ‘Green Light user group’ will launch easy read information leaflets in November. These explain what mental health is and how you can expect to be supported.

Big actions that are starting to make a difference include:

- writing agreements, with help from people with learning disabilities, that say how services will work together better
- trying out a joint assessment tool to help people get the right service at the right time
- working with learning disability and mental health commissioners (people who plan and buy services), to make sure mental health support includes people with learning disabilities
- giving people better support when they go into hospital
- getting community mental health and learning disability teams to work together and support each other more.

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The programme is also looking at what staff do and what is needed to make sure that they have the skills to support people with a variety of needs and wishes. We have asked 'Skills for Care' and 'Skills for Health' to help us with this part of the programme.

To find out more about 'Making It Happen' and see what each site is doing, go to the Valuing People website



or give Ken Holland a call on 07789 653286.



<http://valuingpeople.gov.uk/dynamic/valuingpeople146.jsp>

People in different areas are working together to make mental health services better.

Improving services in ordinary hospitals

The National Patient Safety Agency wrote in a report that going into hospital was one of five big risks to health



<http://www.npsa.nhs.uk/press/display?contentId=2793>



The common difficulties in hospitals include:

- services not talking to each other
- lack of easy read information
- little or no support for family carers
- lack of awareness and understanding by hospital staff about learning disabilities. So there is limited help for people who need it
- hospital staff not knowing about consent to treatment and the Mental Capacity Act.

Sometimes hospital staff do not give a person with learning disabilities the best treatment for their health problem. They might think it will be too difficult. They might think the person will not have a good quality of life.

All these problems need to be improved. There are no national standards for hospitals about care and treatment for people with learning disabilities. So it is really important to learn from each other about what works well.

Examples of what hospitals are doing to improve include:

- plans about working with and supporting family carers
- support from workers in Patient Advice and Liaison Services (PALS). They can help with using hospital services. PALS can also help if something goes wrong. They can help to get things put right early on.

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Some hospitals have an 'acute liaison nurse'. This person's job is to help hospital staff to provide better services for people with learning disabilities. For example, they can train hospital staff and help to make sure the right services talk to each other. One of the problems is that many of these posts are just for a year. Good work they have started may come to a stop.

The Access to Acute (A2A) Network has been meeting since 1999. It is a chance for people to share their good work and develop ideas.



<http://www.nnldn.org.uk/a2a/index.asp>

There are some groups meeting in different regions of the country too.



Contact rick.robson@shropshirepct.nhs.uk

Sometimes hospitals don't work very well for people with learning disabilities. People are working hard in many areas to make this better.

Good practice example in hospital care

The Shrewsbury and Telford Hospital Trust has agreed guidelines for staff in the care of adults with learning disabilities. This shows excellent commitment from acute hospital staff and managers. The Trust has some easy read leaflets on its website



http://www.shropshirepct.nhs.uk/hosp_health_services/Learning%20Disability/leaflets/Leaflets.htm



For example, one leaflet shows step by step what you can expect if you go to hospital for a blood test. Another shows what will happen if you go for a scan.

Visits for carers have been arranged by the Health Access Nurse and PALS to show what you can expect in different departments of the hospital. Members of Taking Part self advocacy group are interviewing ward managers. These interviews will be videoed. We hope the hospital will use these videos as part of their plan to improve the ways they communicate with people with learning disabilities.

The Hospital Trust for Shrewsbury and Telford is doing good work to make their services better for people with learning disabilities.

Independent Complaints Advocacy Service

The Independent Complaints Advocacy Service can support you to raise your voice about health services. We can help you make a complaint if you are not happy with a health service. We can help you make phone calls, write letters, or prepare for meetings. We can listen, and help make sure your voice is heard. We are a free service. We are not part of the NHS. We keep information private (confidential).



Different organisations run the service in different parts of the country. You can find contact details for the service in your region on the Department of Health website at



http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Complaintspolicy/NHScomplaintsprocedure/DH_4087428

You can get help to say if something is wrong with a health service.

More than just a loo

Most of us don't give visiting the shops a second thought. But many disabled people can't visit the shops or go out for a meal because the loos are not good enough. Thousands of people with high support needs cannot use ordinary accessible toilets because there is not enough space or equipment.



Wyre and Fylde Partnership Board decided to use money from the Learning Disability Development Fund (capital money, for buildings) for 'Changing Places' accessible loos. They agreed to use the money with local organisations to make it go further.

They set aside money that could be added if someone was planning a standard accessible toilet. This could be used to make it a 'Changing Place' loo.

They got lots of ideas from local people! People were willing to raise extra money.

The United Reform Church in Poulton-le-Fylde agreed to work with the Partnership Board. They altered their plans and added a fully accessible 'Changing Place'. This has the space and equipment to meet the needs of all local disabled people.

The loo is available 24 hours a day for anyone who has a Radar key



www.radar.org.uk

The main things the 'Changing Place' loo offers are:

- parking spaces for disabled people right outside
- a hoist on the ceiling, with a choice of a medium or large sling
- a changing bed that is big enough for an adult. It can go higher or lower
- grab rails on both sides of the basin.



Lots of people need more than just a loo. Some areas are building good 'changing places'.

A new course for people with a long term illness

The Expert Patients Programme (EPP) is a course for people who have long term illnesses. It helps people to look after themselves and their illness and includes talking about:

- eating healthy foods
- taking medicines and tablets
- relaxation
- coping when you feel low.
- taking exercise
- talking to doctors and nurses
- better breathing

More than 3,000 courses have been run. Over half of people with learning difficulties have long term health problems like epilepsy, diabetes, asthma or depression. Recently the EPP course has been changed to suit people with learning difficulties. This new EPP course has been tried out in 4 areas in England.

The Valuing People Support Team has paid for research by the University of Hertfordshire to look at how well the course has run. They looked at what are the good things about it and what parts did not work so well. They found out that:

- Most people enjoyed the course and lots found it useful.
- It has helped some people to talk more easily to their doctor or chemist.
- It has given people more ideas about healthy eating and exercise.
- Some of the people on the course who needed more support also needed their family carers or support workers to help them understand the course. Their carers or support workers needed more information on the course to be able to really help.
- People really enjoyed the role play used in the course and there could be more of this.
- The DVD and some of the parts of the course need to be changed.

To find out more about the research you can contact Patricia Wilson at p.m.wilson@herts.ac.uk or 01707 286391.

People have tried out a new course for people with long term health problems. They said it was useful. A few bits of the course need to be changed.

Learning Disability Partnership Boards

We know some Partnership Boards have done good work to promote better health and have active health subgroups with good representation from people and families. However, we know some have struggled to make progress and still need to ensure they have:

- A strong relationship with local commissioners and providers of general and specialist health services. In particular a senior PCT representative.
- Good information about the local population of people with learning disabilities and their health needs. This needs to include information about people who may be in a placement out of area like a residential school or secure hospital.
- An up to date 'Action for Health' Framework containing agreed priorities with regular 'checking' on progress at board level.

Importantly, partnership boards should ensure they have taken time to consider the recent reports into general and specialist health services and the action they may need to take locally.

The aim of this information pack is to help people who are members of Partnership Boards to better protect adults with learning disabilities in the communities in which they live. The ideas and suggestions contained in the information pack reflect the views and experiences of many different people and organisations. These people were either experts in terms of long-standing knowledge and practice or experts as a result of their own personal experiences. It is hoped that these informed suggestions will serve to complement, reflect and develop existing work in your particular area.

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UK Health and Learning Disability Network

The Network connects around 1,600 people interested in learning disability and health across the UK. There are 4 networking events every year.



The last one for 2007 is on 2nd November in Birmingham. See www.jan-net.co.uk event page for flier.

Debra Moore (Valuing People Support Team) will be the key speaker.

Contact Janet Cobb on  jcobb@fpld.org.uk to book a place.

The Network is hosted by the Foundation for People with Learning Disabilities and sponsored by the Valuing People Support Team, the Welsh Assembly Government, the Nursing and Midwifery Advisory Group for Northern Ireland and the Nursing and Midwifery Council in Eire.

Further health related networks are available on www.jan-net.co.uk

There is a network for people who want to talk about health.

easyhealth.org.uk

Soon it will be easier to find good accessible health information on the internet!





 In spring 2008 you will be able to click onto easyhealth.org.uk.

You will be able to look at leaflets from organisations like the Elfrida Society and Mencap. You can print most of them. Most will be free.

easyhealth.org.uk will be an important library for anyone who prefers health information that is easier to understand.



generate → easyhealth.org.uk is being developed by Generate. It has been paid for by the Department of Health.

Contact Jo Giles on  01323 760101 or  jo.giles@generate-uk.org for more information.

Soon there will be a website with lots of easy read information about health.

NHS Campus money from the Department of Health

Over the summer there was an announcement that there was £175million capital- money to help buy homes for people who are leaving NHS campuses. The money is spread over 3 years. There was just a short amount of time to bid for money this year and results about who were successful will be announced very soon. There will be more chances to ask for some of the money in November. Details will be sent out to all the campuses. If you want to know more about this you can contact Sue Carmichael by emailing her at



Sue.Carmichael@dh.gsi.gov.uk,

or get in touch with your regional adviser.

Safeguarding Adults with Learning Disabilities

This is an information pack to help Partnership Boards work well to stop abuse from happening and help people who have been abused. It is sent separately with this newsletter. We hope you find it helpful. It is also on our website at  **www.valuingpeople.gov.uk**.

Many thanks to all those who worked so hard to do this for everyone.

Finally.....we know that there is still a lot of work to be done. We also know there are a lot of people, groups and networks out there working hard to make positive change happen. You help us all in different ways – thank you!

A big thank you to Alison Giraud-Saunders and Janet Cobb at the Foundation for People with Learning Disabilities for their help in editing this newsletter, and to all our contributors.

As always, we ran out of space and were not able to include everything people sent to us. However, if you want any further information, please contact me at:



Debra.Moore@dh.gsi.gov.uk

