

Foundation Stones

www.learningdisabilities.org.uk

Issue 17 Winter 2008

Good health?

The NHS and people with learning disabilities

Pages 4 - 5

PLUS...
The chance to win
an iPod Shuffle!
See page 8

INSIDE THIS ISSUE...

Latest news Page 2

Malta Page 3

Review of a residential service in Malta

Who decides? Page 6

How is the Mental Capacity Act working for people with learning disabilities?

We can dream Page 7

Person centred approaches for young people with autism

Foundation for People with Learning Disabilities

News

Consultations

England has a care and support system that aims to help people to be independent, active and healthy throughout their lives. Because we are all living longer and have changing expectations, this system needs to change.

To inform the discussion about how the system will change, the Government wants to hear what you have to say about the principles behind a new care and support system, how the responsibility for care and support can be shared and how clear and fair rules about funding can be set.

Your comments need to be submitted before the end of November and will only be used to inform the Government's plans to change the care and support system. These plans will be outlined in a Green Paper in 2009. To have your say visit

www.careandsupport.direct.gov.uk

The Foundation Recommends...



Banking on Good Decisions



The Mental Health Foundation has produced information (including an easy read document) about how the Mental Capacity Act 2005 can help people with mental health problems and learning disabilities deal with their money when they go

into banks, building societies and Post Offices.

To order a copy telephone **020 7803 1101**

or download for free at

www.mentalhealth.org.uk

The Role & Effectiveness of Learning Disability Partnership Boards

On behalf of the Learning Disability Task Force, Mencap recently commissioned work into the effectiveness of Learning Disability Partnership Boards. The work was completed by Rachel Fyson and Liz Fox, University of Nottingham.

To download a free copy visit

www.mencap.org.uk

or **www.nationaldirector.org.uk**

Antenatal Screening

Parents-to-be aren't getting the right information on Down's Syndrome screening.

We found that parents feel they don't have enough time to consider options – both in terms of whether to have screening and what to do if they find their baby is likely to have Down's Syndrome*. Fathers are often not included in discussions – many midwives only involved fathers if they 'happened to be there'.

Respondents were critical about the negative way having a child with Down's syndrome is often presented – focusing on potential medical problems rather than a balanced picture.

We commissioned this research because we believe that parents should have the best possible information on which to make their own decisions. We are optimistic that the results will be used to improve services.



Project Updates

* Research funded by the Foundation for People with Learning Disabilities and carried out by the University of Plymouth and University of Ulster.

The Choice Forum

To join the Choice Forum visit
www.learningdisabilities.org.uk

Ask Questions
Find Answers
Share Ideas

Hot Topics

The Choice Forum is our online discussion forum where you can speak about everything related to people with learning

disabilities. It is a great place to get or give advice, reflect on the big or small issues in people's lives and examine how we can support people better. It keeps you up to date with all the current information you need to do your job or to live your life more easily!

Recent topics discussed include:

- People with learning disabilities getting married
- Advice about advantages energy tariffs
- Using red and green cards in meetings
- Who pays staff wages when they support people to have holidays?
- Going to the cinema for free

To join please visit **www.learningdisabilities.org.uk** and follow the online forums link!

Malta

In April, the Foundation was invited to review the services provided by Id-Dar tal-Providenza, an organisation that supports 110 people with learning disabilities living in Malta. Id-Dar tal-Providenza was aware of the Foundation's work through their membership to the Choice Forum.

The team set off unsure of what to expect, except that learning disability services often reflect the culture of the country in which they are located. We were keen to respect the local culture and values whilst ensuring that our own experience and knowledge helped to improve the lives of disabled people on the island. We were grateful that most people, including self advocates, used English as their second language.

Malta is predominately Catholic and funding for Id-Dar tal-Providenza is provided solely through voluntary contributions and by the Church. It seems that although Malta has been in the EU for three years, it hasn't yet tapped into European funding that we have long grown accustomed to in Britain.

The commitment of staff to the people they support was high across the services, although living arrangements varied with some single rooms and shared flats, and most people sharing bedrooms. About one third of residents lived in hospital-style units that were clean, but provided limited privacy.

While family ties to the organisation's clients were usually well maintained and families were respectful of the organisation, neither they nor their relatives were able to influence the plans for the individual's life or the strategic direction of the organisation. Yet we met articulate family members who wanted to contribute to both. The managers of the service



acknowledged this untapped potential and showed an interest in including families and self-advocates in the planning and delivery of the service in the future.

We were impressed with the work on 'Special Religious Development' which engages people on an emotional and spiritual level, including people who don't use words. In this initiative we detected an element of person centred planning and an attempt to make social connections with the wider community.

The biggest challenge remains how to get people living in smaller, family-sized houses in the community, participating in ordinary community activities. Does that sound familiar? It's been on our agenda here in the UK for 20 years and we still have much to do! We hope to keep working with our colleagues in Malta helping them to achieve change and build on their sense of community.



For more information about service reviews please contact
Barbara McIntosh on
07801 290575
or email
bmcintosh@fpld.org.uk



The team at Id-Dar tal-Providenza

Key Points

The Foundation went to Malta to see a service where people with learning disabilities live.

We helped them to think about what was good, what was not so good and how they could make things better.

Good health?

The NHS and people with learning disabilities

"I believe that it is possible to deliver effective healthcare for people with learning disabilities and reduce... an unacceptable level of avoidable health risk"

Sir Jonathan Michael (Michael, 2008)

"The vision...is of an NHS that gives patients...more information and choice...and has quality of care at its heart"

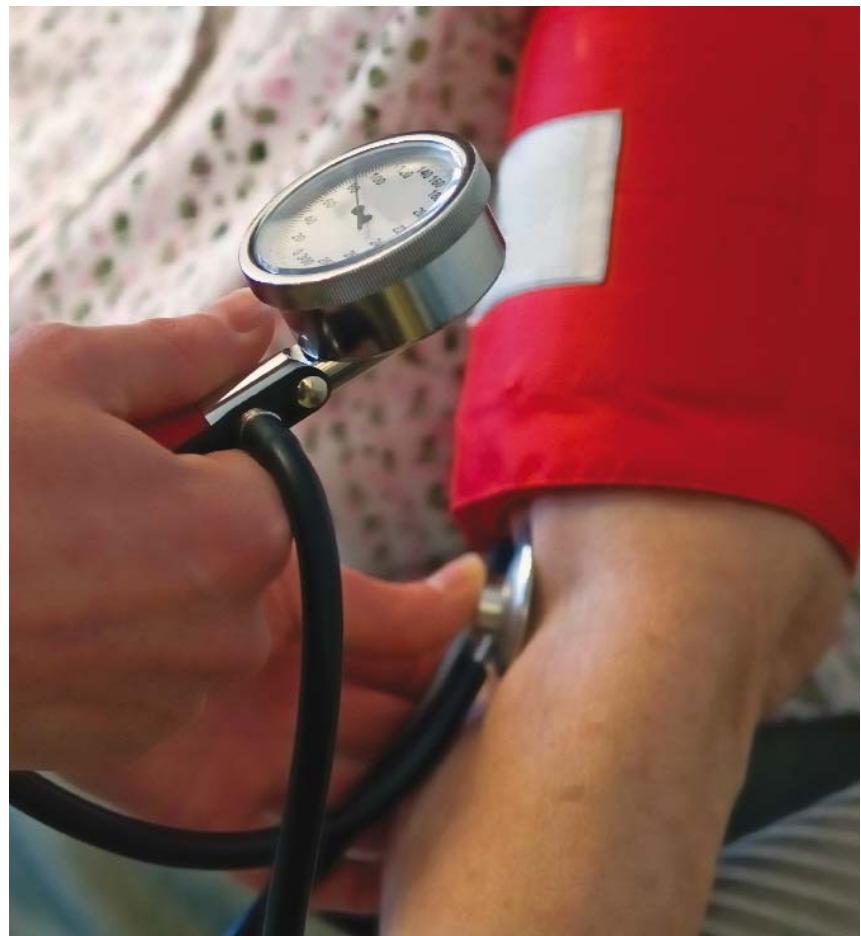
Lord Darzi (Department of Health, 2008)

People with learning disabilities often experience worse health and worse health care than the rest of the population. A series of high profile reports have shown this. However, it doesn't have to be this way - these same reports and our project work over the last eight years also point to good and excellent practice where the NHS takes seriously its responsibilities for the health of people with learning disabilities.

Why isn't this happening everywhere? Often, good work has been done by one or two committed people. Sometimes, short term funding has been used to start improving access to primary or acute care. In both cases improvements can be fragile – progress is lost when a 'champion' leaves or project funding ends. As noted in 'Healthcare for All' (Michael, 2008), people with learning disabilities have been invisible to the NHS and there has been no mechanism to check that they get a fair service.

The best progress is where Primary Care Trusts (PCTs) adopt a strategic approach that includes:

- appointing a lead such as a strategic health facilitator to focus on improving the health and health care of people with learning disabilities
- introducing regular health checks and using the results to inform planning to address gaps in services
- supporting providers of primary and secondary treatment and care to improve their services, including appropriate 'reasonable adjustments'
- capturing data to monitor health inequalities
- helping people with learning disabilities and their families to look after their own health
- training and education for social care services to ensure that they play their part in supporting people to be healthy.



Key Points

People with learning disabilities often have poor health and poor health care.

In some places the National Health Service is giving people with learning disabilities a good service.

People who go to services for people with learning disabilities will now get a health check every year.

Key sources of good practice guidance and support

Networks and information

Access to Acute network www.nnlndn.org.uk/a2a/

Health facilitation network mark.bradley@oxleas.nhs.uk

Mental health in learning disabilities network steven.hardy@kcl.ac.uk

UK Health and Learning Disability Network www.ldhealthnetwork.org.uk or via Janet Cobb jcobb@fpld.org.uk

Additional networks www.jan-net.co.uk

Published resources

Cole, A. and Gregory, M. (2004) Green light for mental health. London: Mental Health Foundation

Department of Health (in press) Health action planning and health facilitation: good practice guidance. London: Department of Health [updates the original guidance]

Department of Health (in preparation) Guidance for the NHS on implementing the Disability Equality Duty with regard to people with learning disabilities

Disability Rights Commission (2006) Suite of guidance accompanying Equal Treatment: closing the gap. London: Disability Rights Commission [now available from the Equality and Human Rights Commission]

Giraud-Saunders, A., Gregory, M., Poxton, R., Smith, C. and Towell, D. (2003) Valuing health for all. London: Institute for Applied Health and Social Policy, King's College London [now available from the Foundation for People with Learning Disabilities]

National Patient Safety Agency (2007) Problems Swallowing? Resources for health care staff. Ensuring safer practice for adults with learning disability who have dysphagia, London: National Patient Safety Agency

Poxton, R. (2007) 10 questions to ask if you're scrutinising mainstream health services for people with learning disabilities. London: Centre for Public Scrutiny

Primary Care Contracting (2007) Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care. London: Primary Care Contracting

Primary Care Unlimited, Valuing People Support Team and Foundation for People with Learning Disabilities (2007) Suite of practical resources for learning disabilities health checks. London: Primary Care Contracting

Smith, C., Giraud-Saunders, A. and McIntosh, B. (2004) Healthy lives. London: Foundation for People with Learning Disabilities

Some Strategic Health Authorities (SHAs) have led improvements in their areas such as introducing a self-assessment framework for PCTs. Two SHAs produced specific reports addressing the health inequalities faced by people with learning disabilities as part of their contributions to Lord Darzi's recent wide-ranging review of the NHS.

We campaigned for annual health checks for people with learning disabilities. So we are delighted that the Department of Health has recently announced a national scheme to offer these to people who are known to learning disability services. We hope this will be extended to others, such as prisoners with learning disabilities.

There is a great deal of good practice guidance and support available to PCTs and practitioners (see box for key examples). There is also lots of information about where to target improvements, such as:

- getting the basics of primary care right
- improving access to acute hospitals and the care offered in them
- improving access to mental health services
- looking after the health of family carers
- addressing the gaps in specialist care for people with complex health needs (e.g. postural care; management of pain and distress; management of dysphagia).

We believe there is enough information about what needs doing and how to do it. People with learning disabilities and their families say,

"it's time to get on with it!"

¹Disability Rights Commission (2006) *Equal Treatment: closing the gap*. London: Disability Rights Commission

Joint Committee on Human Rights (2008) *A life like any other? Human rights of adults with learning disabilities*. London: TSO

Mencap (2007) *Death by Indifference*. London: Mencap

Michael, J. (2008) *Healthcare for All. Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities* www.iahpld.org.uk

Who decides?

Research into how the Mental Capacity Act is working for people with learning disabilities.

The Mental Capacity Act is a law that supports people to make their own decisions, and protects people who have decisions made on their behalf.

The Act is particularly important for people with learning disabilities, who may not have been allowed to make their own decisions in the past.

Marcus Jepson, from the Norah Fry Research Centre at Bristol University is leading a new research project to find out how the law is working for people with learning disabilities and their supporters.

The research, supported by the Foundation, must also follow the requirements of the Act. So, it is assumed that each of the 10 or so people with a learning disability involved in the project can decide independently to take part. They are being given support to make that decision by:

- meeting Marcus to find out about the project
- having family members / supporters present
- being offered accessible information about the project
- being given time to ask questions and change their mind at any time.

After getting to know Marcus people are asked if they want to take part in the research. Those that do agree prepare a decision-making 'map' of the sorts of everyday decisions that they're involved in. After the 'maps' have been produced Marcus uses a video camera to record the people making some of those decisions.

This is a particularly exciting way of doing research because it captures decision-making as it happens. After each session Marcus and the participants review the recording and discuss it. People have enjoyed being recorded although at first they have been a little unsure about how they look on camera!

For more information about this project please contact Marcus Jepson on **0117 331 0987** or email marcus.jepson@bristol.ac.uk



Marcus Jepson, from the Norah Fry Research Centre

Initial findings from the study will be available in the next few months and an accessible summary in October 2009.

The research will be of interest to policy makers who want to know how the Act has been translated into practice. Examples of good practice from the research will be useful to anyone who supports someone to make decisions or makes decisions on their behalf.



Marcus is working towards a PhD funded by the Economic and Social Research Council (ESRC). His work is being supported by the Foundation as part of our programme of work on the Mental Capacity Act. For more information visit our website at www.learningdisabilities.org.uk

→ Key Points

The Mental Capacity Act is a law that supports people to make their own decisions.

We have been finding out how this law is working for people with learning disabilities.

We can dream

In Foundation Stones 15 we wrote about 'We Can Dream,' a project helping four young people with autism and their families to use person centred approaches to life after school. Now the project has ended we can tell you what we have learned from it.

As Melanie's story (below) shows, person centred planning can work for young people with autism. However, several tools we have developed for people with learning disabilities may need to be adapted for people with autism.

Firstly, take time to understand how he or she prefers to communicate and make decisions.

Secondly, for some, using colourful graphics or having too many people at planning meetings is overwhelming.

Thirdly, many people with autism find the words used in person centred approaches too abstract. 'Dreams', 'wishes' and 'gifts' are less meaningful than concrete phrases, such as 'what do you think you are good at?'

Fourthly, people with autism are too often labelled as having 'obsessions' rather than valued for their talents. Focusing on these talents can really help the person think about their future.

Melanie's story:

Melanie lived away from her family and was about to leave school. She and her family gathered a small circle of support to ask what she would like to do with her life.

Melanie was clear that she wanted to move back to her home area to keep in touch with her school friends and attend their college. She was also keen to continue attending after-school clubs and activities because she met her friends there.



Melanie in her new home

Now, Melanie studies at the college and with the help of a housing social worker, has moved in with three other young people. She has re-established contact with her school friends and goes swimming regularly.

Kelly, Melanie's Mum says:

"Mel has benefited a lot from being involved with the Foundation. Without it she couldn't have reached her full potential. Mel was really listened to and this gained her confidence. She's very happy in her new home."

To find out more about how to help young people with autism think about life after school, you will be able to download a copy of the We Can Dream information booklet in the new year at www.learningdisabilities.org.uk



For more information about We Can Dream contact Jill Davies on **020 7803 1141** or email jdavies@fpld.org.uk

Key Points

Person centred planning may need to be changed when working with young people with autism.

Fundraising and events

Building Community Networks Annual Conference

The latest in our series of annual events will focus on learning the lessons from the Foundation's *Life in the Community* project.

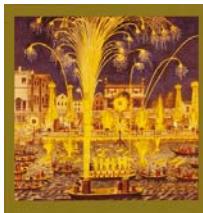
The project has helped more than 30 people with high support needs find positive roles in their communities. The day will be both a celebration of their achievements and an opportunity to learn what helped make it all happen. Highlights will include:

- short films telling the story from each of the sites that took part, culminating in an awards ceremony
- the launch of guidance about how to get a community connecting service off the ground
- essential information for commissioners and managers of services
- interactive workshops
- research findings from the evaluation of the project
- the national perspective about why the project has important lessons for Government policy
- a performance by Moveable Feast.

The conference will be on Wednesday 18th February at the Wellcome Collection, London. Please contact Harriet Gardner on **020 7803 1159** or email **hgardner@fpld.org.uk** to book a place. To find out more about the networks please visit www.choiceforum.org/buildingcommunitynetworks

Christmas Cards

Buy your Christmas cards directly from us and all profits will be used for our vital work in helping people with mental health problems and learning disabilities. There are four designs to choose from:



Fireworks and
Illuminations



Holy City



Snowy
Country Lane



Nine Fat Robins

All cards are priced at £3.50 for a pack of 10

Special offer: Buy 2 packs, get one pack of Holy City for just £1
P&P 60p for 1 pack, £1.20 for 2-5 packs, £2 for 6 packs or over.

Please call **0207 803 1121** or email **supporter@mentalhealth.org.uk** to place your order.

London 10,000k run

Take in the most famous sights of the capital whilst running part of the Olympic Marathon route for 2012. This race is perfect for both novice and experienced runners alike. To join our team or to find out more information please contact our events team on **020 7803 1123** or email **events@mhf.org.uk**



To find out different ways you can get involved and support our work please visit our website at www.learningdisabilities.org.uk/get-involved

Win an iPod Shuffle

We hope you like the new look of Foundation Stones. The redesign is part of our ongoing commitment to make the magazine accessible and informative, keeping you up-to-date with our work and the important issues that affect people with learning disabilities.



Next Spring's issue will also be available in a new electronic format as **Foundation Stones Extra**. This will allow readers to view the magazine on a PC or laptop and share it more widely with others. The electronic format will also mean that we can include longer articles and provide links to useful resources.

Whether you prefer to go on receiving your paper copy of Foundation Stones or you would like to receive the new **Foundation Stones Extra** update your contact details and get the chance to win an iPod Shuffle.

Please update your contact details and tell us whether you would like to receive a paper copy of Foundation Stones or the new electronic **Foundation Stones Extra** by emailing **fpld@fpld.org.uk**

Closing date: 9th January 2008.