

Foundation Stones

www.learningdisabilities.org.uk

Issue 15 Autumn/Winter 2007

Campaign for better funding!

The Learning Disability Coalition is made up of ten voluntary organisation members (the Foundation being one of these) campaigning to highlight the funding shortfall in learning disability services. The Coalition is chaired by Jo Williams from Mencap and co-ordinated by Heather Honour, its campaigns manager. Heather is working with Coalition members to produce evidence that greater investment is needed to ensure that policy directives within *Valuing People* (the government's plan for making the lives of people with learning disabilities and their families better) can be put into effect. The Coalition has already met the Minister, Ivan Lewis, and the King's Fund to seek support.

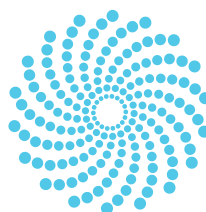
Coalition members are concerned about cuts in post-16 education, altered eligibility criteria for social care, withdrawal of funding by Primary Care Trusts and closure of day centres where no positive alternatives are in place. Ensuring quality of life for people with high support needs is another area of concern.

The Coalition is planning to undertake a review that will identify:

- the resources needed to provide services, taking account of changing demands and needs
- where the deficits lie
- where funding is being used effectively
- the likely impact of self directed support and individual funding
- where savings could be made.

With this evidence the Coalition will be well armed to campaign for improved funding.

Please help! The Coalition has a target to reach: ten thousand signatures by late October, to deliver to the Prime Minister at Number 10 Downing Street. We need all of our supporters to sign the online petition. You can do this on the Coalition's website at www.learningdisabilitycoalition.org.uk



**Learning
Disability Coalition**



For more information about the Coalition contact Barbara McIntosh on **07801 290575** or email **bmcintosh@fpld.org.uk**

Key Points

The Learning Disability Coalition is a group of 10 charities.

The Coalition is trying to get more money for learning disability services.

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**Foundation for People
with Learning Disabilities**

UK Health and Learning Disability Network



The Network connects over 1600 practitioners (and others) who have an interest in learning disability and health issues across the UK. It is free to join. Two of the important themes discussed by Network members are health checks and care in acute hospitals.

Health checks

People with learning disabilities face considerable inequalities in access to health services, as demonstrated in the Disability Rights Commission Formal Investigation into health inequalities, *Equal Treatment: Closing the Gap*.

The Department of Health has made a formal response and action plan, *Promoting Equality*.

There are a number of key issues for Primary Care Trusts (PCTs) to consider:

- the evidence of health inequalities and poor outcomes for people with learning disabilities is strong – is there any reason to believe your PCT area is different from the rest of the country? Do you have a strategic health facilitator post to help you address this?
- PCTs are legally required under the *Disability Equality Duty* to act on evidence of inequalities. Failure to do so may leave them open to prosecution.
- comprehensive health checks are both the best way to change these poor outcomes and a clear way for PCTs to demonstrate compliance with legal requirements.

To help PCTs with this agenda the *Primary Care Commissioning Framework* for people with learning disabilities has been developed by the Department of Health Primary Care Contracting team, with support from the Foundation.

Acute hospital services

Serious patient safety and treatment issues have been highlighted in several recent reports, including Mencap's *Death by Indifference*.

All the reports point to improvements required in acute hospital services. An Independent Inquiry into access to health care for people with learning disabilities is now under way.

We know that some areas have invested in acute liaison nurse posts to help hospitals improve. Working closely with strategic health facilitators, they are really making a difference. The UK Health and Learning Disability Network is gathering evidence of both problems and good practice to submit to the Independent Inquiry.



Have your say! To join the Network visit www.learningdisabilities.org.uk/ldhn or contact Janet Cobb on **07980 754448** or email jcobb@fpld.org.uk

The UK Health and Learning Disability Network is hosted by the Foundation 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.

Key Point

The UK Health and Learning Disability Network members are talking about:

- **health check ups for people with learning disabilities**
- **better care in hospital.**



Publications referred to in this article:

Equal Treatment: Closing the Gap visit: www.drc-gb.org/library/health_investigation.aspx

Promoting Equality visit:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072955

For guidance on the *Disability Equality Duty* in the health sector visit:

http://www.drc-gb.org/employers_and_service_provider/disability_equality_duty/sectoral_guidance/health.aspx

Primary Care Commissioning Framework visit: www.primarycarecontracting.nhs.uk/204.php

Death by Indifference visit: www.mencap.org.uk/html/campaigns/deathbyindifference/index.asp

What Kind of a Future? Leading meaningful lives after school and college

From talking to people with Down's syndrome, their families and researchers, we know that many young people find it hard to build and maintain social networks and to find work and leisure activities to keep them busy and fulfilled. Even amongst those young people who attended mainstream school, very few go on to hold paid employment. It appears that opportunities for social inclusion narrow as young people reach their mid to late teens.

Legacy gifts form an important part of the Foundation's annual income, enabling us to develop innovative projects to help people with learning disabilities. In December 2005 we were delighted to receive a legacy of £153,000 from a generous supporter to improve the lives of people with Down's syndrome. *What Kind of a Future?* is an action-based project focusing on creative ways to enhance social inclusion for young people with Down's syndrome after school and college.

We have stories to show that some young people lead more active lives and have a greater community involvement. They often seem to be those who have experienced some of the more innovative approaches, including person-centred planning, self-advocacy, circles of support, and individual funding such as direct payments.

By working with national organisations such as the Down's Syndrome Association, the Down's Heart Group, Down's Syndrome Scotland and the Down's Educational Trust, we are collating evidence from some of the young people who have benefited from such approaches. During the past few months we have been talking to people across England, Wales and Scotland and have been enthused by their stories. By the end of the year we will produce a booklet promoting their experiences to inspire others, which will be available to download for free from our website (www.learningdisabilities.co.uk). During 2008 we will carry out work to see if the innovative approaches are successful for other young people living in the UK.

i If you would like more information about this project please contact Jill Davies on **020 7803 1141** or email jdavies@fpld.org.uk

For information about leaving a legacy gift, please contact Sue Whitehead on **020 7803 1124** or email swhitehead@mhf.org.uk



Chris Philpot spoke to us about his life

Key Points

The Foundation is talking to young people who are doing what they choose with their lives.

The Foundation wants to find out what helped them to do those things.

A life in the community?

The Foundation's *Life in the Community* project is entering its third and final year. The main aim of the project is to find innovative ways of helping people with significant disabilities to play a greater role in their communities. Molly Mattingly from the Foundation is helping four independent services from different parts of the country provide person-centred support to 30 people with learning disabilities. Paul Swift is leading an evaluation team of self-advocates, family carers and people who work in learning disability services to find out whether the project makes a difference to people's lives and, if so, how. The project findings will show other services what they can do to support people in similar ways.

Where are we up to now?

When people were recruited to the project, we took a 'snapshot' of their lives: how they spend their time, the important people in their lives, their use of community facilities, and so on. Above all we wanted to know what they and their families wanted to happen. At the end of the project we will compare this information with the current situation to find out whether or not their lives have changed much.

To find out whether any changes are as a result of the project we are monitoring the support provided. We have asked the four services to describe in their own words how they are getting on. Periodically they come together to hear one another's stories and help each other overcome problems. During a recent round of visits the evaluation team asked questions, based on research and good practice, about what was happening. In the autumn the team will go back to ask other local organisations for their observations of what the services have done and to find out what other important people, such as commissioners, are doing to help the service meet its aims.

What has the project achieved so far?

The 30 people involved have very different needs and aspirations and therefore the rate at which they are able to achieve those aspirations will vary. But a feature of the project has been the detailed planning that has taken place, often for the first time in a person's life. Staff within the services have acted as catalysts for this. For example, the co-ordinator at the Brandon Trust has been instrumental in developing a circle of support for each person there to help achieve the type of lifestyle they want. She has also introduced care staff to the ideas behind 'community mapping' and 'community capacity building'.

The project has demonstrated the importance of working with families to get things done. At the service in Darlington, a family identified a business opportunity for their son and his friend based on their particular culinary skills. The Wm Morrison Trust is now helping to develop the business idea behind JJ's Soup Kitchen (business partners John and John are pictured).

Understandably, some families worry that opting for a new, community-based support service may jeopardise their relative's eligibility for a long-established local authority service, such



JJ's Soup Kitchen

as a day centre. And some are concerned at the amount of responsibility placed upon them by the idea of 'self-directed support'. In Coventry, the Grapevine service has addressed this by offering help, advice and guidance to a young woman and her family applying for an individual budget. Having help to navigate local funding systems can be the key to getting good long-term solutions to families' concerns about community-based support.

"Sarah's life has changed dramatically as a result of the project...this is only the beginning of things improving for Sarah... there's no two ways about it Sarah's life is limited... and I will be looking for more."

Father of Sarah, a participant in the project

What about the next year?

The challenge for the coming year is to turn all this planning, scoping and mapping into action. This needs to be supported by creative commissioning. The Tamarisk Trust service has been most successful in this respect because Barnet's commissioning team and local day services have been actively involved in the project. This has led to a more joined-up approach to creating individual opportunities for people who need more support.

Yet the Government's policy of modernising day services is not being exploited everywhere to support this group of people in community settings. For example, in one of the project areas the local authority has opted to build a new day centre to cater

for people with high support needs. The sort of creativity or flexibility in funding that was envisaged with the introduction of individual budgets is not available in all areas. The positive influence of the project, apparent amongst all of those who have taken part in it so far, now needs to be brought to bear upon the key decision-makers at each of the services.

To learn more about how each of the services involved in the project have been moving things forward, come and meet them 'live' at the third annual *Building Community Networks* conference (see page 8).

i For more information about *Life in the Community* contact Molly Mattingly on **07787 500184** or email **mmattingly@fpld.org.uk**

Key Points

This project is about ways to help people with learning disabilities to have a bigger place in their communities.

Good things have started to happen because of this project, like groups (circles) of support, a new business and individual budgets.

Launch of *Having a Good Day* practice guide

As part of Social Care Institute for Excellence's work on helping people with learning disabilities to 'have a good day', a practice guide has been produced, highlighting what services can do to ensure this happens.

In national policy, people are described as 'having a good day' when they are:

- doing things that have a purpose and are meaningful to them
- doing things in ordinary places, that most members of the community would be doing
- doing things that are uniquely right for them, with support that meets their individual and specific requirements
- meeting local people, developing friendships and connections and building a sense of belonging.

The practice guide, *Community-based day activities and support for people with learning disabilities*, is about:

- building community opportunities and support so people can have ordinary daily lives
- day service modernisation
- community-based services
- employment, lifelong learning, leisure, relationships and more.

The guide is aimed at planners, commissioners, care managers, managers of services and people in direct support and community building roles, and includes research evidence, policy, examples of good practice, checklists, practical hints and tips and suggestions about where to get more information.



Having a good day

i To download this practice guide or the briefing for local advocacy groups and self-advocates visit **www.scie.org.uk/publications/practiceguides**

To download the knowledge review or easy read knowledge review visit **www.scie.org.uk/publications/knowledgereviews**

For more information about *Having a Good Day* contact Molly Mattingly on **07787 500184** or email **mmattingly@fpld.org.uk**

Key Point

A book (practice guide) has been written to help get better day activities and support for people with learning disabilities.

Making change in Cornwall

In the last issue of Foundation Stones we mentioned the work we are doing in partnership with Cornwall County Council. Over the past year work has focused on:

- developing more community based day opportunities
- supporting people to undertake person centred plans
- developing a more individualised short breaks service
- helping people set up their own businesses through our *In Business* project.

We have begun a leadership course for self-advocates and at the beginning of next year will start working with families to help develop their leadership role in planning and delivering services. We will also be helping self-advocates develop small businesses to sell handmade art and jewellery.

Since we began working in Cornwall, important changes have taken place. First, the Healthcare Commission investigation into the abuse of people at Budock Hospital led to its closure and 14 people moved to the community. Each person now has their own bungalow and has chosen their own service provider. Second, following a course that we delivered in Penzance, more people have circles of support.

In November we are holding a celebratory event at the Eden Project to highlight the potential of people with learning disabilities who live in Cornwall.



We will hold a celebratory event at the Eden Project in November



For more information about the Foundation's work in Cornwall contact Barbara McIntosh on **07801 290575** or email bmcintosh@fpd.org.uk

Key Point

The Foundation is doing lots of work to get better chances for people with learning disabilities and their families in Cornwall.

In Business

In Business, a new project established to support people with a learning disability to become self-employed, started in June. The project will support small business development that is owned and managed by an individual, using their skills and interests. For some, self-employment offers a chance to have control over their working life and reap the financial rewards!

In Business aims to:

- work with up to six sites in England
- create opportunities in both rural and urban areas, working with local authorities, colleges and voluntary sector organisations
- raise awareness about self-employment as an option
- link with mainstream businesses to gain support
- support people to set up their own businesses
- capture learning, good practice and the effects of business culture on day service modernisation
- produce a step by step guide to the processes involved.



In Business is supported by a Department of Health grant and Cornwall County Council.

For more information contact Keith Bates, the project manager, on **07796 053847** or email kbates@fpd.org.uk or Barbara McIntosh on **07801 290575** or email bmcintosh@fpd.org.uk

Key Point

The In Business project is helping people with learning disabilities to start their own businesses.

In memory of Alison Tucker

By Hazel Morgan

We are sad to report the death of Alison Tucker from cancer earlier this year. Last year in a memorable celebration at the Globe Theatre we launched the DVD, *Faith in Practice*, which she directed and produced with Mabel Cooper, Gloria Ferris and Jason Samuels. We never dreamed that this would be the last time the Foundation worked with Alison.

She had earlier produced and directed videos for the Foundation's GOLD (Growing Older with Learning Disabilities) programme and for the training resource, *Learning with Families*.

Alison's empathy ensured that those she interviewed responded warmly and honestly to her. People enjoyed working with her as she was sensitive, thoughtful and professional, always striving for the best.



Alison Tucker

Alison had been with the Open University from 1978, going freelance in 2000. She will be greatly missed. We extend our sympathy to her partner, Patrick Marrin.

i *Faith in Practice*. Available from the Foundation. Telephone **020 7803 1100** or fax **020 7803 1111** or email **publications@fpld.org.uk**

Learning with Families: A Training Resource. Available to download for free from **www.learningdisabilities.org.uk**

Supporting Women with Learning Disabilities Through the Menopause, a resource pack. Available from Pavilion Publishing. Telephone **0870 890 1080** or visit **www.pavpub.com**

Key Points

Alison Tucker made three videos for the Foundation.

We are sad because she died earlier this year.

We Can Dream!

We Can Dream is a pilot project addressing transition for young people with autistic spectrum disorders. People with autism have unique needs and many talents, but traditional services after leaving full-time education may not help them and their families think more creatively about how they can achieve their dreams. People on the autistic spectrum risk being left out of person centred approaches and individual budgets.

We are supporting a small group of young people and their families to develop self-directed ways of achieving a meaningful life. Everyone wants something different. For example, one young woman wants to move from her residential home to a house with young people close to her college. A young man wants to pursue a job working in the music industry or in a record shop and move into a flat with a friend.

The Foundation is working in partnership with the National Autistic Society (Bexley) and with local authorities in Brent, Redbridge and Waltham Forest to make this possible. We plan to produce some good practice guidelines by the Spring of next year.



Key Point

We are helping young people with autism to think about what they want to do after they leave school.

i For more information contact Jill Davies on **020 7803 1141** or email **jdavies@fpld.org.uk**

Extra news

Older families

We are delighted to have received a £70,000 grant from the Lloyds TSB Foundation for a three year project, which is looking at people with learning disabilities who take on caring roles for their older relatives. The grant adds to funding already received from the Calouste Gulbenkian Foundation and the Valuing People Support Team. Work has already started in four sites – Shropshire, Leeds, Barnsley and Norfolk – so watch this space! If you would like to be kept in touch with this work, please contact Dalia Magrill at dmagrill@fpld.org.uk

Building Community Networks

The Foundation will hold the third Building Community Networks conference in December 2007 at the newly opened Wellcome Collection in London.

The event theme will be 'Inspiring one another to include people with learning disabilities in our communities', with internationally renowned Dave Hingsburger as key speaker.

Please contact Gillian McEwan on **020 7803 1159** or email gmcewan@fpld.org.uk to book a place. To find out more about the networks please visit www.choiceforum.org/buildingcommunitynetworks

Celebrating the life of someone special

Receiving donations in memory of someone special is an honour. You can now have your own Tribute Fund in the name of your loved one to receive gifts from family and friends. We will send you regular news on how your fund is growing and ideas to help you fundraise, together with updates on our work.

For more information please contact Jayne Cromwell on **020 7803 1152** or visit www.fpld.org.uk/intribute

The Flora London Marathon 2007

Well done and a big thank you to all of our 64 runners who took part in the Flora London Marathon in aid of the Mental Health Foundation. To date the team fundraising total is well over £110,000.

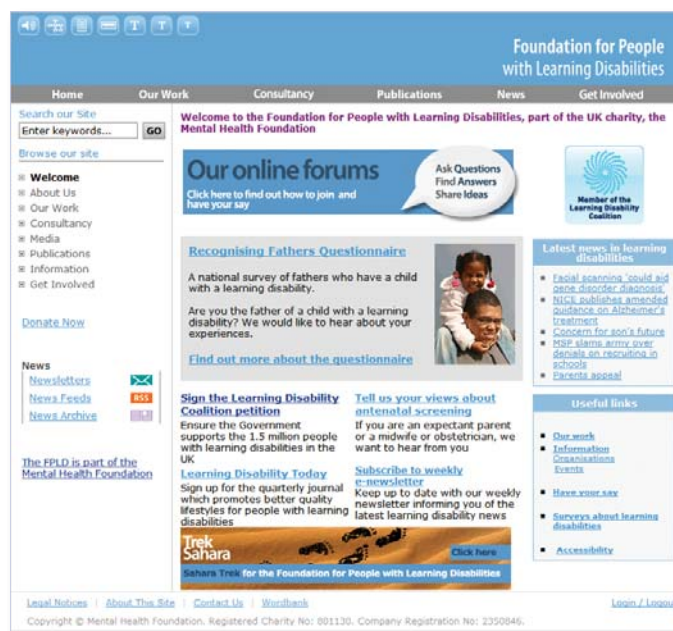
Inspired to run next year? Please visit www.crunch.org.uk/mhf or call **020 7803 1123**.



Jackie Mascall and Molly Mattingly

New website for the Foundation

The Foundation's new-look website explains all about our work and offers publications and DVDs to download or order online. There is a range of information on learning disabilities, a daily news service and directories of organisations, websites and events. Visitors can ask questions and share ideas through our forums. Visit us at www.learningdisabilities.org.uk

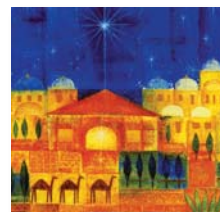


Christmas cards

Buy your Christmas cards and help support our work! Choose from our two beautiful designs, 'Holy City' (£2.99 per pack of 10) or 'Snowy Country Lane' (£3.99 per pack of 10). To order please telephone 0207 803 1121 or visit www.learningdisabilities.org.uk

or www.mentalhealth.org.uk

*P&P 60p for one pack, £1.20 for 2-5, £2 for 6 and over.



Key Point

This page is about our new projects, events and fundraising.

Photographs on pages 2 and 7 from Photosymbols.

