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New initiative will help services meet needs of older family carers

Older family carers are the focus of a new three-year initiative from the Foundation for People with Learning Disabilities. This major partnership project aims to help learning disability partnership boards across England identify and meet the needs of this neglected group.

The initiative will start with a detailed survey of how local authorities in England work with older family carers. The results will enable the project to develop a range of materials and services for learning disability partnership boards, older family carers and workers, including:

- **consultancy** to support local partnerships in developing their services for older family carers and their families
- **good practice guidance**
- regular **newsletters** highlighting good practice, resources and links
- the **older carers network**
- **regional seminars and conferences**
- **learning sets**, which will be piloted for frontline workers and will focus on supporting good practice
- **evaluation** of targets for working with older families, set out in Valuing People.

Focusing on Older Family Carers

Valuing People acknowledges the longstanding neglect of many older family carers and identifies them as a priority.

A number of learning disabilities organisations are taking part in the older family carers initiative, which is funded by a Department of Health section 64 grant. Partners in the initiative include: the British Institute of Learning Disabilities (BILD), Home Farm Trust (HFT), Housing Options and Carers UK. The project will also work closely with Cally Ward, a member of the Department of Health's Valuing People support team.

The initiative takes forward work begun in the Foundation's GOLD (growing older with learning disabilities) programme. ■



1st issue of newsletter



Dalia Magrill, project manager, older family carers initiative

For further information on the older family carers initiative or a copy of the Family Futures newsletter, please contact Dalia Magrill or 020 7802 0329 or email: dmagrill@fpd.org.uk ■

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Friendship is central to growing older happily and healthily, report concludes

As people grow older it is important to value and protect their friendships and social activities

Opportunities need to be created for people to try new activities and make new friends

Today & Tomorrow: The Report of the GOLD Programme

The right to make and keep friends is as important for older people with learning disabilities as access to good health care and housing, according to the report of the growing older with learning disabilities (GOLD) programme. The report, *Today and Tomorrow*, says that friendships are crucial for emotional well-being. It sets out a charter of rights, including assistance in starting and maintaining friendships.

Opportunities for Friendship

Today and Tomorrow was launched in October as the four-year GOLD programme drew to a close. Friendship emerges as one of the key themes of the report, which focuses on identifying and meeting the needs of older people with learning disabilities and older family carers.

Yet, the report concludes, people with learning disabilities often have few friends. Growing older makes it even harder to maintain friendships and get involved in social activities.

Today and Tomorrow reveals that many older people with learning disabilities want the opportunity to build relationships with people beyond their immediate circle of carers and staff. However, service providers tend to concentrate on enabling older people with learning

disabilities to take part in activities. This focus, combined with insufficient resources, may prevent friendships from developing outside services. People living on their own may also become isolated and lonely unless they are helped to maintain social networks.

The Foundation wishes to thank Dr David Thompson for his work as GOLD programme manager from 1998 to 2002. ■



Betty, Michael and Pat from the Gold Over 50's Saturday Group

GOLD programme resources

Today & Tomorrow: The report of the GOLD Programme is now available from the Publications department tel. 020 7802 0304 or email: books@mhf.org.uk Priced £27.50 Professional/£12 unwaged plus 10% p&p

The GOLD video is also available from the Foundation for People with Learning Disabilities, tel: 020 7802 0304. Cost: £11.80 (incl p&p), or buy the **GOLD VIDEO** and **TODAY & TOMORROW** and save 25 per cent off the price of the video: £35 professional/£19.50 unwaged plus 10% p&p.

Supporting women with learning disabilities through the menopause by Michelle McCarthy. This illustrated resource pack contains training materials, exercises, loose-leaf guides and a video, is designed to help residential and day services staff support women through the menopause. Further details from Pavilion at www.pavpub.com, tel. 01273 623222

Dementia pack from the British Institute of Learning Disabilities (BILD) available shortly, contact BILD for further information tel. 01562 723010 ■



A charter of rights for older people with learning disabilities and for older family carers

Throughout the UK, there is a growing awareness in government of the needs of older people with learning disabilities and older family carers. But they are still a frequently neglected minority. Their interests need to be higher on the politicians' and service providers' agendas.

Good health is essential for achieving independence, choice and inclusion. (Valuing People white paper)

The Foundation calls for older people with learning disabilities to have the right to be supported to:

- develop person-centred plans to meet their current and future needs
- develop and maintain new friendships
- maintain links with their families when they have left home
- lead full lives with activities of their choice both during the day and also at evenings and weekends
- have a choice about where they live and with whom
- have access to services which can adapt to their predictable, age-related needs, in staffing and in their environment
- have access to independent advocacy
- have their physical and mental health needs met. They should have access to regular health check-ups, screening (including screening for the early onset of dementia if they have Down's syndrome) and to prompt treatment if they become ill
- have their religious, cultural and ethnic needs respected
- be cared for in terminal illness, as far as possible in a familiar environment, in a way that respects their wishes.

The Foundation calls for older family carers, to have the right to:

- receive the practical and emotional support needed to continue to care for as long as they and their family member who has learning disabilities wish. Support should include the provision of information, short-term breaks and access to support groups
- peace of mind that the needs of their family member who has a learning disability will be met when they are no longer able to care full-time or after their death
- have support in their caring role. Their family member with learning disabilities should have access to a range of activities outside the family home or additional support within the home
- have access to an independent advocate
- have their religious, cultural and ethnic backgrounds respected
- request an assessment of their needs as carers.

Planning needs to take place over a period of time and at the pace that the family wants, when a family carer reaches the age of 60

The Foundation is grateful to all the companies and charitable trusts supporting GOLD, in particular the Baily Thomas Charitable Fund, the Charles Hayward Foundation, Comic Relief, the Bartley Trust and the Abbey National Charitable Trust

Count us in – report launched

Up to 40 per cent of young people with learning disabilities are likely to experience mental health problems at any one time according to the findings of a year-long Inquiry from the Foundation for People with Learning Disabilities. The final report, 'Count Us In: Meeting the Mental Health Needs of Young People with Learning Disabilities' also found that young people with learning disabilities aged 13 to 25 are much more likely to develop mental health problems than other young people.

We must face up to the fact that often we do not serve these young people well. There are pockets of good practice worthy of replication, but in the UK we do not have a cohesive, multi-disciplinary service framework capable of delivering good mental health (Professor Barry Carpenter)

The 26-member committee led by Professor Barry Carpenter, met six times over the course of the year to consider a range of evidence from more than 250 people. This included feedback from focus groups, presentations by family carers, professionals and researchers, submissions from young people with learning disabilities and several commissioned papers. Two young people with learning disabilities, Emma Wilson and David Green, also acted as advisors to the

inquiry. Emma and David held focus groups with other young people with learning disabilities and reported back to the committee at each meeting.

Promoting emotional well-being

The inquiry took as its starting point the importance of emotional well-being. The committee highlighted the need to boost young people's confidence and emotional resilience to prevent mental health problems occurring and heard about factors which promote well-being, including strong role models and relationships, early, practical and emotional support for families, a decent income and good housing. Young people with learning disabilities are particularly at risk of developing mental health problems, so it is really important that they are supported through periods of change and transition in order to help them maintain a positive sense of well-being and self-esteem.

In certain cases one step to

improve mental well-being is encouragement and help in maintaining a social network, yet the report found this wasn't being offered. Many young people commented that hanging out with friends made them feel good and family carers pointed out that giving young people the opportunity to make decisions about their lives enabled them to feel empowered. They also need work and/or meaningful activities as young adults.

The committee heard about known risk factors for mental illness, including learning disability itself, abuse, racism, bereavement, economic disadvantage, physical illness and lack of self-worth. It found that young people with learning disabilities are susceptible to bullying, abuse, social exclusion and low self-esteem. Many also live below the poverty line. Dr Andrew McCulloch, Chief Executive of the Foundation said: "These factors alone mean they're likely to develop treatable mental health problems, yet time and again, we've heard from them and their families that they're not getting the support that they need."



A conference on meeting the mental health needs of young people with learning disabilities:

- March 4 2003 in Glasgow in partnership with the Scottish Consortium for Learning Disability and Pavilion

For details, contact: Pavilion Conferences, The Ironworks, Cheapside, Brighton, East Sussex, BN1 4GD, tel 01273 623222, email info@pavpub.com or see www.pavpub.com

More help needs to be available at difficult times for the whole family

He [the doctor] saw the disability first and the person second

More needs to be done to train health and education professionals to consult the child or young person with learning disabilities, with an emphasis on listening, valuing what the child or young person has to contribute and using non-verbal means of communicating

She gets great satisfaction from having the house to herself for a while, letting her helper in and making her a cup of tea

Accessing appropriate services

The Inquiry agreed that government and services have an important role to play in promoting good mental health as well as supporting people with problems. However the committee heard time and again that young people with learning disabilities who develop mental health problems lack clear routes into treatment. There were frequent delays in getting help. "The most common approach to responding to the needs of young people with learning disabilities is 'no response' until problems have escalated to the point of significant risk," said one nursing manager.

Is this because, as one parent suggested, we see the disability first and the person second? Mental health problems such as depression and anxiety are often wrongly perceived to be part of the disability and young people with learning disabilities often put

up with these mental health problems when the rest of the population rightly expects treatment.

Most parents complained that there is a lack of information and forward planning for the transition from children's to adult services. Some parents felt that no one takes responsibility for young

adults who experience mental health problems. "[There is] no service at all in our area for young adults under 18 who need secondary specialist intervention," commented one social worker.

To order Count Us In, the report of the inquiry, please ring 020 7802 0304, price £27.50 plus 10% p&p.



Emma Wilson (right) and dance group

My baby sister makes me happy. My family makes me happy as well

Other people being happy. Happy music. The outdoors. Friends. Family. People making compliments

What makes Jo feel good is when he is made to feel valued

The Foundation for People with Learning Disabilities is grateful to the Baily Thomas Charitable Fund for their support for the inquiry

Summary of Recommendations

- Mainstream health services should develop the resources and expertise necessary to respond to the needs of young people with learning disabilities
- Specialist learning disability services should be developed as a resource for mainstream services and to support those young people with the most complex needs
- There should be clear protocols for referral and/or care pathways for young people with mental health problems
- Local services should be sensitive and responsive to the needs of young people from minority ethnic communities
- There is an urgent need for further research on meeting the mental health needs of young people with learning disabilities
- Families and young people need appropriate information about promoting their health, including their emotional well-being
- The need to improve the quality of life of young people with learning disabilities should be specifically addressed in national plans and by all relevant statutory services.
- Schools and colleges should promote and sustain positive mental health through their ethos and curriculum
- The Special Education Needs co-ordinator or another member of the teaching staff should have responsibilities for providing information and support for young people with mental health problems
- Staff training needs should be addressed, for example there could be development of shared learning at induction, in service and at undergraduate and postgraduate level about the needs of young people who have mental health problems.

Opening up accessibility to services for young people from minority ethnic communities needs to be improved

We need to listen to what young people and their families have to say about their experiences of anxiety and depression

The mental health needs of young people with profound and multiple learning disabilities has long been overlooked

If Connexions gets it right, there is a real opportunity to help this group of young people with learning disabilities make a smooth transition to adult services

The Foundation is grateful to the Baily Thomas Charitable Fund for supporting the research programme

Young people's mental health projects get £300k boost

Improving access to services

Four research projects, costing almost £300k, aimed at improving access to high quality services for young people aged 14 to 25 with learning disabilities and mental health problems are being funded by the Foundation for People with Learning Disabilities.

Foundation trustees approved the projects, from a large number of applications, as part of a two-year research programme.

"All the projects offer something unique and we are pleased that there are two projects that focus on groups that have been

overlooked: people from ethnic minority communities and those with profound and multiple learning disabilities," said Jill Davies, research programme manager.

"We are also very pleased to have two projects that prioritise the views of young people with learning disabilities; one, during transition to adulthood via the new Connexions service and the other, when addressing depression and anxiety.

"All the projects involve young people with learning disabilities and their family carers in the research process and in assessing



Jill Davies, Research Programme Manager

the different perceptions of mental health problems. We hope to produce models of good practice that we will be able to share." ■

The four projects

Using a liaison worker in a multi-ethnic inner city population

Dr. Raghu Raghavan of the University of Bradford is studying the needs of Pakistani and Bangladeshi young people with learning disabilities and mental health problems, where language and cultural differences make it harder to access services. ■

What's happening?

Alastair Wilson and Dr Andrew Jahoda from the Strathclyde centre for disability research, University of Glasgow, are leading research into what young people with learning disabilities understand by anxiety and depression, its treatment and its impact on their lives. It will also look at how parents and carers deal with their younger relatives being anxious or depressed. ■

Identify the needs of young people with multiple and profound learning disabilities

Professor James Hogg from the University of Dundee is overseeing this project. It aims to identify the existence of mental health difficulties in young people with profound and multiple learning disabilities and will look at how services respond to these difficulties. ■

Mind the gap

Dr Pauline Heslop of the Norah Fry research centre in Bristol will be working in partnership with Somerset Joint Commissioning team and the Connexions Service to identify and overcome the barriers to services for those young people with a learning disability and mental health problems who are making the transition to adult services. ■



Dr Raghu Raghavan

Spirituality and the needs of people with learning disabilities

Spirituality has been defined as the human quest for "meaning, purpose, self-transcending knowledge, meaningful relationships, love and commitment, as well as the sense of the Holy among us." (Swinton 1999)



Dr Chris Hatton

Progress

Spirituality serves as a source of personal strength and comfort in people's lives. That is one of the early findings from research conducted by John Swinton of the University of Aberdeen as part of a two-year programme, Meeting the Spiritual Needs of People with Learning Disabilities.

The programme, comprising two complementary projects run by Dr John Swinton and Dr Chris Hatton of the University of Lancaster, was launched last January. Dr Swinton is consulting with people with learning disabilities and their carers on their views about meeting their spiritual needs.

Dr Hatton is developing and piloting guidance and resource material for staff on meeting religious needs. ■



Dr John Swinton

Forthcoming events

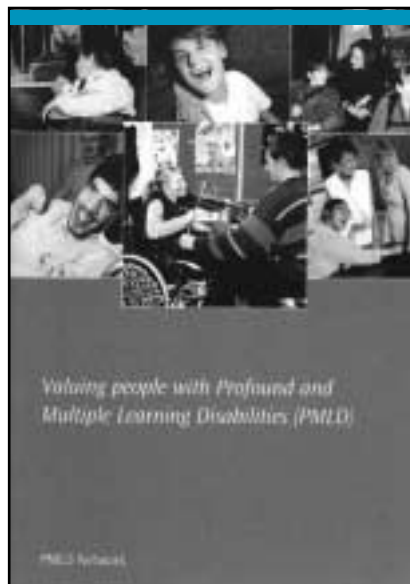
- Meeting the Spiritual Needs of People with Learning Disabilities, Glasgow seminar, January 30 2003. Contact Marsha Parsons mparsons@mhfd.org.uk at the Glasgow office for an invitation. Places are limited.
- Spirituality conference on 28 May 2003. Contact Pavilion Conferences on 01273 623222, email: info@pavpub.com or look at web site www.pavpub.com for further information.

If you would like to be kept informed about this programme, please contact Patricia Umolu by email: pumolu@fpld.org.uk or telephone: 020 7802 0330

Supporting people with profound and multiple learning disabilities

The PMLD network, which was created in November 2000, works to help support people with profound and multiple learning disabilities. It has produced a response to the learning disabilities white paper, Valuing People, including recommendations for further action.

To find out more, please contact Beverley Dawkins (national officer for PMLD), Mencap, 123 Golden Lane, London EC1Y 0RT or email: beverley.dawkins@mencap.org.uk ■



I don't need to worry too much when things go wrong. God watches over me... I suppose I trust him... He cares

God loves me and looks after me, even when I am bad

The Foundation for People with Learning Disabilities is grateful to the Shirley Foundation for their support for the Spirituality Programme

Children and adults with profound and multiple learning disabilities are probably some of the most marginalised people within our society

This issue of Foundation Stones is edited by Anna Hewitt, Hazel Morgan and Linda Steele

Each individual should have the support and opportunity to be the person he or she wants to be

Certificate in working with people who have learning disabilities: your pathway to achievement

At least three quarters of the 83,000 people in England working in learning disability services have no relevant qualification; only 13 per cent are studying for one. The government has acknowledged that the skills, training and qualifications of the workforce need to be improved.

The learning disabilities award framework (LDAF) provides a route to qualification for staff supporting people with learning disabilities. The Foundation, the Tizard Centre (University of Kent) and Pavilion Publishing have developed a course programme and supporting materials, including a trainer's toolkit and student workbook to enable students to achieve qualifications.

To obtain Your Pathway to Achievement contact Pavilion Publishing on 01273 623222 or email: info@pavpub.com. For further information about LDAF, visit www.ldaf.org.uk



What's going on at the Foundation for People with Learning Disabilities and the Mental Health Foundation

Welcome to our New Chief Executive

We are pleased to welcome Dr Andrew McCulloch as the new chief executive of the Mental Health Foundation and Foundation for People with Learning Disabilities. Prior to joining the Foundation in September, Dr McCulloch was Director of policy at the The Sainsbury Centre for Mental Health for 6 years and contributed to a number of key reports and projects including Keys to Engagement, Acute Problems, Finding and Keeping, Pulling Together and Breaking the Circles of Fear. Andrew was also a senior civil servant in the Department of Health for 16 years and was responsible for mental health and learning disabilities policy from 1992 to 1996.

The policy forum

To coincide with the publication of Valuing People, the policy forum was set up to provide an arena for the discussion of policy issues affecting the lives of people with learning disabilities throughout the UK. Current issues include continuing health care, the transition process, self-advocacy, person-centred planning and family carer representation on partnership boards. To join, visit www.learningdisabilities.org.uk or email nmorris@fpld.org.uk

Publications

Dr John Swinton (2002) Space to Listen: Meeting the spiritual needs of people with learning disabilities. University of Aberdeen. £15.00 plus p&p.

Learning Disabilities - the Fundamental Facts £22.50 plus 10% p&p.

Foundation publications catalogue online at www.learningdisabilities.org.uk

Updates: Research and Policy Briefings from the Mental Health Foundation. Volume 4 covering topics from dementia and advance statements to the mental health needs of young people with learning disabilities. To subscribe, call 020 7802 0304 or email: books@mhf.org.uk

For more information on publications, call 020 7802 0304 or email fpld@fpld.org.uk

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