

Are people 'Having a Good Day?'

The Valuing People White Paper stated that people with learning disabilities should be having a full and purposeful life within the community, but how successfully are services helping people to achieve this? The Social Care Institute for Excellence (SCIE) asked the Foundation for People with Learning Disabilities and the Norah Fry Research Centre to find out, and find examples of good practice.

Research published in the last 10 years was examined. People providing services, people using those services and families were asked to give examples of good practice. This is what the research found:

Planning with people

Very little person centred planning is taking place even though it can help people get the support they want and need.

Support into adulthood

Where person centred planning is happening, more young people are benefiting and some adult services are working with schools to help students prepare for life after school. But services must get better at working together to support young people at this crucial time in their lives.

Work

There is increasing support from day service staff to help people find and keep a job. However, despite many people with learning disabilities wanting to find work, the numbers in employment are still small and only a few people had been helped to set up their own businesses.

Having a social life

Some community facilities, such as swimming pools and leisure centres, are encouraging people to get a better social life, although work still needs to be done in many areas to help people make and keep friendships.

People with high support needs

In most places, people with high support needs still spend their day in a centre, even though there are ways that staff can help to involve them in their communities.

Some tips for making this happen:

- Think about opportunities in the community
- Connect with people who are 'out there' already
- Make person centred approaches more central
- Support people to plan activities starting out from where they live
- Good leadership is really helpful (values, training)
- Tell people about 'success stories'
- Business culture helps especially when seeking jobs
- Develop staff skills in individual working and community connecting
- Use individual budgets and direct payments to increase choice and control.



Derek Docherty runs his own car washing business



If you want help to improve day opportunities contact Barbara McIntosh bmcmintosh@fpld.org.uk

The full report is available on both the Foundation's and SCIE's websites.

Thank you to SCIE for commissioning this work.

Key Points

The Foundation has been working on a project to make day services better for people with learning disabilities.

The Foundation has been looking at which services are doing well and not doing well.

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Life in the Community

Community inclusion for people with learning disabilities and high support needs

As day services are modernised, it is a real challenge for organisations to include people with learning disabilities who need a lot of support.

We are excited to announce our new, two-year action research project 'Life in the Community', which will explore how people who need a lot of support can be more included in their communities.

Four voluntary organisations have been selected to take part in the project. They were chosen because of their innovative ideas about how they will work with their local authorities to support young people and adults who have learning disabilities and high support needs to become included members of their communities.

The four organisations that have been selected to take part in the project are:

- The Brandon Trust, Bristol
- Grapevine, Coventry and Warwickshire
- Tamarisk Trust, Barnet
- Wm Morrison Enterprise Trust, Darlington.

Each organisation will work with 10 people with high support needs and will receive financial support from the Foundation and their local authority. They will also get consultancy and advice from the Foundation to establish a programme of training and service development.

An evaluation and support team will ensure that things are progressing well within each organisation. This team will include people with learning disabilities, family carers and practitioners.

Workshops will bring together representatives from all of the organisations to learn about what is working well, what barriers there are and how they can be overcome. Feedback from these workshops and the evaluation and support team will help to inform the development of services.

Reports, articles and seminars will draw out good practice and seek to influence policy in this area.

Outcomes

We anticipate that:

The people with learning disabilities who are participating in the project will enjoy greater involvement in community life and be able to exercise their rights and responsibilities as contributing citizens.

Communities will gain greater awareness of how people with high support needs can engage in, and contribute to, mainstream activities.



Alan Wood and Jonathan Smith are being supported by Wm Morrison Trust to find jobs in their communities. Alan wants to work in a garage and Jonathan wants to work as a baggage handler at the local airport.

This project and 'Having a Good Day?' (see front cover) will allow us to draw out practical learning and models of good practice. These will contribute to:

- Influencing national and local policy makers, commissioners of services and practitioners to pursue successful inclusion in the community for people who have high support needs
- Supporting local authorities to have a greater understanding of what is meant by real community inclusion and how to commit to the continuation and development of inclusive community support services
- Implementing the 'Our health, Our Care, Our Say' White Paper objectives, ensuring that the needs of people who need more supports are not overlooked.



For more information contact:

Molly Mattingly – Project Co-ordinator
mmattingly@fpld.org.uk or 020 7803 1149

Key Point

This work will give people who need a lot of support more opportunities to do exciting things.

We will help other people to learn from this work.

Faith In Practice:

A resource for faith communities to include people

To be able to express your faith is a fundamental human right, yet some people with learning disabilities who want to belong to a faith community do not get the support they need.

A new film has been produced by the Foundation to help faith communities include people with learning disabilities. The video production team - Mabel Cooper, Gloria Ferris, Jason Samuels and Alison Tucker - interviewed people with learning disabilities and faith leaders from some of the major religions. The team said "We hope it will help people understand people with learning disabilities and make them welcome."

The importance of faith

The film highlights the importance of people's beliefs in their lives. Bernard talks about his Jewish faith as his 'identity'. Shak tells us that Islam means everything to him. Sarah and John speak about how their Christian faith helps them in their daily lives. Moninder's mother talks about how her two sons value going to the Gurdwara and listening to Sikh music each day. Kalpesh and his mother are Hindus and perform daily worship at home.

Including people

The faith leaders reflect on how they have included people in their communities. For example, Dilowar Khan speaks of the importance of accessibility and enabling people to lead ordinary lives. The president of the Gurdwara describes how they communicate with Moninder. Gregory has become Bernard's friend and helps him to learn Hebrew. He supported him in preparing for his Bar Mitzvah. Keith has a number of roles in his Anglican church including greeting the congregation.

"We hope it will help people understand people with learning disabilities and make them welcome."

The purpose of the video

The aim of the film is to encourage faith leaders to:

- Talk about including people with learning disabilities in their faith community and about what they contribute.
- Talk to people with learning disabilities about what they value, the support they need and how they might like to contribute more.
- Think about what else they could do to help people with learning disabilities be included in their faith community.



The film production team: Mabel Cooper, Jason Samuels & Gloria Ferris



You can order the film, **Faith in Practice**, on VHS or DVD. It is available from the Foundation priced £12.50 including p&p. It is free to people with learning disabilities and their families.

Please ring 020 7803 1101 or email publications@fpld.org.uk

For more information about our spirituality work visit www.learningdisabilities.org.uk or call Marie Broad on 020 7803 1143.

Key Points

The Foundation has made a film to help faith communities to include people with learning disabilities better.

On the film, people with learning disabilities talk about their faith and being part of a faith community.

Listening to advice

We want the Foundation's work to be guided by what is important to people with learning disabilities, family carers, and those who support them.

We have started three new advisory groups to help us plan and review what we do:

- A group of people with learning disabilities to tell us what is important to them
- A group of family carers to tell us what is important to families
- A group that reports to the Foundation's Board of Trustees about work that the Foundation for People with Learning Disabilities should be doing. This group is chaired by one of the Trustees and includes a mixture of people from the two groups above and people with expertise in research, housing, education, health, service management and commissioning.

All of these groups will meet twice a year. They include representatives from different cultures and different parts of the UK.

The first meetings were held in February and March. We were delighted that so many people attended and shared our view that the Foundation needs to listen to the perspectives and ideas of a wide range of people.

Advisory groups have already helped us develop our plans for 2006/07. For example, the Foundation has learned that it needs to do more to share information and tell people about its work. We will look at how we can improve this, using our website, networks and publications.

Key Points

The Foundation has set up groups of people to help plan our work.

The groups include people with learning disabilities, family carers and people who do different types of work with people with learning disabilities.



"As a person with a learning disability, it is important to work alongside the Foundation for People with Learning Disabilities to make things better." Pat Charlesworth, Self Advocate



"How refreshing to find such a warm and sympathetic team eager to listen to us and keen to encourage us to expand on our experiences, needs and hopes. (And what a contrast to the usual 'consultation' which so often amounts to being told what authorities have already decided to do)." Derek Hill, Family Carer



We would be delighted to hear what you think about this!

Please contact Alison Giraud-Saunders
agiraud-saunders@fpld.org.uk

Help with teenage emotions

Kelly is 19 and lives with her mum. Two years ago she developed epilepsy, which made her feel very unhappy. She did not go out much, felt lonely and began to argue a lot with her mother. Eventually she got support from the local social services department and now goes to college and attends a weekly social club.

Kelly's story features in a new DVD called **What's Happening?** It's about the lives of three young people with mild to moderate learning difficulties who have experienced emotional problems during their teenage years. Kelly, Peter and Stephen took part in a research study funded by the Foundation. They wanted to help other young people by showing what happened to them. They and their carers talk about the issues they faced and what help enabled them to feel better. The DVD also features an introduction by Scottish dance music star, Mylo.



Kelly talks about her life

Key Point

Three young people have made a DVD about what made them feel sad and worried.



“To my shame I had not noticed how Stephen had withdrawn because he did not know exactly what was going on and was looking to his family to make sense of his loss.” Stephen's Mum

i The **Well-being Workshop** pack costs £35.00. To buy a copy please contact us on 020 7803 1101 or email publications@fpld.org.uk

Key Point

There is a training pack to help carers to support people who need lots of support and who feel sad or worried.

i The DVD is £5.00 for young people/family carers or £15.00 for professionals/organisations. To buy a copy call us on 020 7803 1101 or email publications@fpld.org.uk

For help to improve support for young people, contact Jill Davies at jdavies@fpld.org.uk

Thank you to the Baily Thomas Charitable Fund.

Recognising mental health problems in people with high support needs

Research by the Foundation shows that identifying mental health problems in people with profound and multiple learning disabilities can be difficult.

The Foundation has produced a new training pack to help carers overcome this. The **Well-being Workshop** pack was developed by family carers to focus on the more common causes of mental health problems, including: change and transition; health issues; loss and bereavement; and supportive therapies.

Stephen's story

Stephen became withdrawn when his grandmother died. However, his family were so trapped in their own grief they did not recognise how it affected Stephen.

The family tried to help him by showing him photographs of happy times with Grandma and explained that she was tired and needed to go to sleep for a long time. Before her death Stephen's grandmother recorded her voice to be included in a Christmas present and the family play this periodically to him. This has been hugely beneficial in contributing to Stephen's understanding of his grandmother's death.

Thank you to the Baily Thomas Charitable Fund.

Get involved, raise some money and make a difference!

The Foundation for People with Learning Disabilities, as part of the Mental Health Foundation, relies on money from a number of sources. The generosity of donors enables us to carry out valuable projects, independent of government and services.

Trek Peru 14th- 23rd September 2006

Take part in an experience of a lifetime and help raise funds! Immerse yourself in Peruvian culture and trek along one of the world's most stunning trails to Machu Picchu.

Visit www.learningdisabilities.org.uk/challenges for more information. Alternatively contact our Fundraising department on 020 7803 1125 or email events@fpld.org.uk for a free information pack.

Chariot Lottery

Would you like to support the Mental Health Foundation and have the chance to win up to a million pounds at the same time?

The Mental Health Foundation is involved in a new type of weekly lottery which is being launched this spring. The Mental Health Foundation will be one of the charity partners directly benefiting from Chariot's new Charities Lottery, which hopes to raise over £150 million for charities each year. We'll keep you posted about when you can play and support us directly – please register your support at www.chariotlottery.com

Legacy brings parents lasting benefits

Legacies can enable supporters to make a lasting mark on the work of the Foundation and the lives of people with learning disabilities and their families. One such supporter, Robert Leonard Haines, included a gift in his Will that helped fund the Foundation's *First Impressions* project, which aims to provide emotional and practical support to families raising a young child with a learning disability. With his gift, we were able to publish an informative booklet for parents as well as a detailed report for services.

Legacies give people an opportunity to plan a gift that will benefit generations to come.

If you would like to receive information about leaving a legacy, please call Sue Whitehead, our Legacy Officer on 020 7803 1124 or write to her at the Foundation for People with Learning Disabilities.

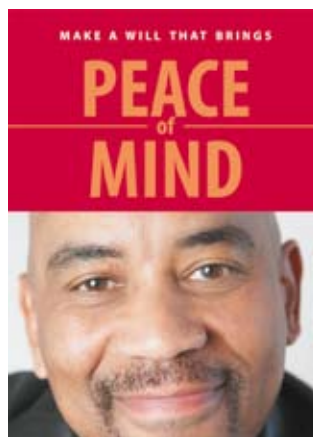
Fancy a trip to The Big Apple?

Why not run for the Foundation in the ING New York Marathon in November? Reach the fundraising target of £2,250 and receive your flights, guaranteed entry and accommodation for free!

To experience the thrill of crossing the finish line in Central Park, call us on 020 7803 1125 for a free information pack or visit www.learningdisabilities.org.uk/challenges



View from the Sun gate overlooking Machu Picchu at the end of the Trek



A leaflet about leaving a legacy to the Foundation



Crossing the finish line in the New York Marathon!



For details about any of these fundraising events or for information about how to donate to the Foundation, please call 020 7803 1125 or send an email to fundraising@fpld.org.uk

Key Point

This page is about how you can raise money for the Foundation for People with Learning

Supporting Older Families: Mutual Caring

The Older Families Initiative has highlighted a group of people who are at particular risk of being overlooked.

People with learning disabilities are often supported and looked after by their families. However, as their family carers age, many people with learning disabilities become carers themselves. Often this happens with very little recognition or support from services. This is known as 'mutual caring' because both people are dependent on one another. The needs of family carers are often overlooked, but people with learning disabilities who are carers are even less likely to be given information, help and choices that would help them in their role. Providing practical and emotional support to their ageing relatives is something that many people see as very natural and something they want to do, however there is a great deal that services could offer to make things easier for families where mutual caring is happening.

Maureen's story

Maureen lives at home with her elderly mother in Shropshire and they both look after each other. Maureen is very proud of the help she gives to her elderly mum, but has found things very difficult in the past. Some of the things she's struggled with include carrying the shopping, feeling safe at home and having breaks from caring so that she could see her friends and go to church. Maureen told us "Not enough people listen. I felt I was struggling until people started to listen to me."

Once people realised how much Maureen was caring for her mum, they were able to offer her more help. Flick Penal, the Shropshire Carers Link Officer, adapted the Carer's Assessment and arranged for Maureen's key worker to help her complete the form. As a direct result, Maureen had a hand rail installed to help her get in and out of her house with the shopping, got a personal alarm and someone to spend time with her mum so that Maureen could get out more.

"Not enough people listen. I felt I was struggling until people started to listen to me."

Maureen

Maureen agreed to go to Northern Ireland with Dalia Magrill as part of the Foundation's Older Families Initiative to tell people about her experiences and to help other people understand how important it is that people like her are recognised and given the right help and support.

Older Families Initiative – the future

The Foundation for People with Learning Disabilities is continuing its commitment to promote good practice in supporting older families of people with learning disabilities. The Foundation is hoping to focus more on the issue of mutual caring in the future, as well as continuing to provide opportunities to highlight initiatives that are working well for older families across the country.



Maureen Hobley on her way to Northern Ireland – her first time flying!
"I was very frightened at first but then I thought it was lovely. I got to meet the plane driver."



For training and service development in the area of older families, contact Dalia Magrill by email on dmagrill@fpd.org.uk

Key Points

Some people with learning disabilities are doing a lot to help look after their parents as they get older, but they might need more support with this.

The Foundation still wants to help people improve the way they support older families.

EXTRA NEWS

Support for young people in secondary education

What About Us? is a new project being run in partnership by the Foundation and the University of Cambridge Faculty of Education. It aims to look at practical ways to improve the emotional well-being of pupils with learning disabilities who attend mainstream secondary schools and colleges. One focus will be on times of transition, such as moving to a new school or leaving school and starting college. This project is being funded by the Big Lottery Fund.



UK Health and Learning Disability Network

This Network is for everyone who cares about the health of people with learning disabilities. It offers:

- Moderated electronic networking (currently around 1400 members drawn from a wide variety of backgrounds)
- A searchable archive
- Expert input from Janet Cobb, a very experienced practitioner with unrivalled knowledge of who is doing what and where good practice can be found
- Meetings that include interesting presentations and good opportunities for face to face networking.

To join, visit www.ldhealthnetwork.org.uk

Developing family leadership

The Foundation has a history of supporting families to influence and lead local and national policies for people with learning disabilities. Foundation staff Christine Burke and Molly Mattingly have been seconded to the Valuing People Support Team as part-time Family Leadership Co-ordinators. They help local family leadership programmes in the South of England, developing the training and support needed to build a network of families who can continue to affect Government policies. They also help to find funding.

Online forum

The Choice Forum is the biggest, liveliest online discussion forum on issues affecting the lives of people with learning disabilities in the UK.

It brings together over 1,800 people, including people with learning disabilities, national and local policy makers, service managers and commissioners, frontline staff, parents and carers.

For more information about the Choice Forum, please visit www.choiceforum.org

Better lives for people with learning disabilities?

The Foundation has a very active development programme working with organisations, people with learning disabilities and families. We offer staff training, service development and service reviews on a wide range of topics. Present work includes:

- Supporting learning disability services to prepare for CSCI inspection
- Individual assessment/planning for people with high support needs
- Leadership development for families and self advocates
- Developing inclusive education opportunities
- Improving access to health services.

To find out more, please contact:

Barbara McIntosh on 07801 290 575 or email bmcintosh@fpld.org.uk

Alison Giraud-Saunders on 07721 843 290 or email agiraud-saunders@fpld.org.uk

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Key Point

This page is about our new information and events.