Working with older people with learning disabilities:
Lessons from an Age Concern pilot programme
About half of all people with learning disabilities can expect to live as long as the general population and an estimated 29,000 people with learning disabilities are living with a parent aged 70+. Nevertheless, there is considerable evidence to demonstrate that the needs of older families of people with learning disabilities are not being met by services in a ‘joined up’ way.

In response to this, in 2004 the Research & Development Unit published a Practice Briefing – “It’s good to be part of things”: Working with older people with learning disabilities 1 to encourage more local Age Concerns to develop services and activities for older people with learning disabilities and their older family carers. The Briefing highlights some excellent and innovative practice. However, consultation carried out as part of this work confirmed that coverage was far from comprehensive, either by types of service provision or geographical distribution.

Consequently, using money secured from two charitable trusts, a pilot programme was established and members of the federation were invited to submit proposals for a small amount of financial support to undertake work focusing on: empowering older people with learning disabilities, and their families, to identify their own needs and priorities; working with local disability organisations, carers’ organisations, housing, health, and social services to provide more effective, co-ordinated support; and ensuring that older people with learning disabilities maintain strong social networks.

Five projects were selected and have been supported to a maximum of £5000 per year for two years. The programme concluded at the end of 2007.

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Programme specification

The projects focused on one or more of the following areas of work:

- **Supporting inclusion**
  developing relevant training and resources, e.g. ‘Easy read’ materials, information and advice, to assist staff and volunteers to support older people with learning disabilities to participate in community activities

- **Developing partnerships**
  disseminating information, sharing experiences, and providing mechanisms to ensure that the voices of older people with learning disabilities are influencing policy, and supported to contribute to Learning Disability Partnership Boards

- **Research and development**
  supporting initiatives to identify the specific support needs of particular groups, for example, Black and Minority Ethnic (BME) elders with learning disabilities

- **Independence, voice and choice**
  developing advocacy services to enable older people with learning disabilities to voice their needs (e.g. focus groups, listening events, etc), exploring new methods of consultation and ensuring their voices influence policy

The expectation was that the projects would have the potential to:

- Achieve the principles of *Valuing People* \(^2\): independence, choice and inclusion

- Involve citizens with learning disabilities in the development of projects

- Consult with local family carers (e.g. via Mencap and carers’ organisations)

- Respond flexibly to the demands of older people with learning disabilities and their family carers

- Join a project network (for mutual support, shared problem-solving and information exchange)

- Complement, not substitute for, learning disability service providers

- Clearly show sustainability, to promote the future development of practical support services for older people with learning disabilities

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Expected Outcomes

There was a clear vision of the hoped-for outcomes:

For local Age Concerns:
- Improved partnership working, locally and nationally
- More effective consultation with older people with learning disabilities and their families
- Better knowledge of the needs of older people with learning disabilities
- More appropriate and accessible Age Concern services

For older people with learning disabilities:
- Improved access to community facilities and health and social care services
- Better practical support for family carers
- Improved health and stronger social networks

Project locations and focus

The five projects were selected on the strength of their proposals and not evenly distributed across the country. Nevertheless, they were located variously in both large and small cities, urban and rural areas, and multi-racial and multi-cultural areas and represented a reasonable cross section of the federation’s membership.

The range of activities undertaken was broad. Collecting information, consulting with people, raising awareness, improving communications and delivering a service ran through the five projects:

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This simple analysis of project activities immediately highlights awareness-raising as being a component of each of the projects. However, understanding of the term varied according to the specific conditions in each locality, in particular the range of services already provided by that Age Concern, and the principal aims of each project – whether to raise awareness internally of the needs of older people with learning disabilities, or to draw attention to the role that Age Concern might play in people’s lives as they grow older.

So, *raising awareness* meant:

**Coventry:** ensuring that staff and volunteers who might come into contact with people with learning disabilities had a better understanding of their needs and ways of communicating more effectively

**Leicester:** highlighting the specific needs of older people from black and minority ethnic groups within and outside of Age Concern

**Norfolk:** identifying the scope and extent of mutual support activities carried out by people with learning disabilities for their older family carers - and especially parents

**Norwich:** drawing the attention of local authorities and others to the needs of older people with learning disabilities, so that they were included in consultations

**Nottingham and Nottinghamshire:** equipping staff with knowledge and skills to improve responses to people approaching them for services

The meaning of *consulting people* was more consistent, but the methods employed varied:

**Leicester:** interviews with individuals either at service sites (day centres) or in their own homes, to ask what services they and their families wanted and needed

**Norfolk:** interviews with learning disabled people and their family carers to explore their needs, wishes and contributions to the lives of others, conducted by their peers who had been trained in research techniques

**Norwich:** conducting meetings with groups of people, who were resident in the same place – group homes, or members of the same social or recreational group

**Nottingham:** by running consultation groups with people using day services in a number of locations and subsequently through individual discussion

*Improving communications* included both promotional activity, improving ways of reaching out, or sharpening up existing materials so as to be more relevant or accessible:

**Coventry:** identifying other services used by people with learning disabilities to promote knowledge of their project’s service and how it could be tailored to individual needs
Norwich: identifying ways in which existing consultative activity by local agencies could be improved and developed so as to include older people with learning disabilities, and subsequently reviewing their own leaflets

Nottingham and Nottinghamshire: commissioning redesign and rewriting of a series of leaflets so that they were more accessible and improving the organisation’s initial response to enquirers

Collecting information has been a by-product for all projects, but two made this an explicit goal:

Leicester: set out to find out whether black and minority ethnic people were getting services they needed, and whether the register of learning disabled people accurately reflected the number of people from those communities

Norfolk: complemented research that was already underway to establish the needs of older family carers and has provided another dimension to the emerging findings

Case study: Age Concern Nottingham & Nottinghamshire

A member of staff who coordinates a volunteer based befriending project attended a Learning Disabilities awareness-raising session in July 2007. They were also present at a staff meeting that month where a presentation was given on the Learning Disabilities project. At the end of the summer she received an application from a potential volunteer who openly stated that he had a learning disability. The man had picked up an “easy read” leaflet for her service from a local CVS. Because of the knowledge the Coordinator had recently gained about communicating with people with a learning disability, she felt able to interview the person, with the support of one of the people working on the project. As the role involved sitting with an older person for a long period of time, it was felt that the volunteer would not be appropriate for that service. However, he was signposted to volunteer in a day centre and is still enjoying doing arts and crafts with the attendees. Since then, a service user with learning disabilities has been welcomed into the day centre because the other attendees are more comfortable with their behaviour through getting to know the volunteer.
Learning and achievements

Projects set modest goals in line with the small amounts of money and staff time available. One of the major lessons from the pilot programme was that relatively small additional resources used to enhance or expand existing activities could have a big impact on the lives of older people with learning disabilities. For example:

- Redesigning leaflets to be accessible to people whose reading skills are more limited drew attention to the need to consider the content and style of all communications. In Nottingham ‘Easy read’ leaflets were soon popular with all older people visiting the office and led to a review of a wider range of printed materials.

- The commitment to seeking to involve a wider range of people in community consultation, adopted in Norwich, had the effect of bringing a previously excluded group of people into view so that they are now more likely to be invited to contribute their views on a growing range of matters – not only about the care services they use.

- As a result of concerns raised by families, users of services from Leicester’s black and minority ethnic communities are now more likely to receive food suited to their dietary and cultural needs and better information on the range and variety of services available to them.

- In Norfolk the key providers of services for learning disabled people have recognised that their users also have skills, energies and strengths, as well as needs, and that these are being used to support ageing family carers.

- Improving and strengthening practice in a Coventry activities centre has contributed to the organisation’s standing as a provider of quality services and has also led to changes in the range and type of information made available to callers at the main office.

In addition, there has been a growing recognition of the kinds of needs presented by older people with learning disabilities - in some ways no different than any other older person – and this is likely to provide the inspiration for further imaginative service developments.
Organisational issues

Some of the issues that arose during the programme were not specifically related to working with people with learning disabilities, and reflect problems or techniques, which can be relevant to any kind of work.

**Time and timing**
Small projects can be just as time-consuming as significantly bigger enterprises, especially during the start-up phase when connections have to be made with colleagues from other organisations whose help or ‘permission’ may be vital to either the speed or conduct of future work.

Patience and persistence is required in dealing with other organisations that may view Age Concern’s new interest as being marginal or even an unwelcome incursion into their ‘territory’

**Managing small projects**
Projects dependent on only one staff member may be fragile and especially susceptible to delays due to competing demands on time, illness or fatigue. They need active support and encouragement from managers, especially when starting work in what is seen as uncharted territory.

**Confidence**
Staff working in a new field can be slowed down by feeling unconfident about their own or their organisation’s capacity, or by others’ responses to their interest. Managing the transition from acknowledged expert to novice status can be difficult and may be dependent on others.

**Be prepared!**
Confidence can be restored if time is taken to gather information about the language, terminology and jargon associated with a new area of work. Having the confidence to ask what difference there is between learning disability and learning difficulty may seem small, but loomed large for some.

**Gaining access**
Most organisations are cautious about granting access to vulnerable people and families/parents in particular may be very protective, perhaps even obstructive to independent activity. Time has to be set aside to negotiating with carers and professionals when working with people with learning disabilities.
Age, ageing and boundaries
Chronological age may be less important than making an appropriate response to the presenting needs and capacity of someone who could benefit from, or contribute to, the services and facilities Age Concern can offer.

Time to reflect, disseminate and network
When involved in doing something different, new or innovative it is vital to build in time to gather up any learning so that it can be shared with others who are interested or who might contribute in some way.

Different perspectives and new insights
Engaging in a small, specialist project may shine a light into other areas of work. Thinking about improving communications for people with limited capacity to absorb written information may uncover hitherto unacknowledged weaknesses that may have prevented inclusiveness.

Whose work is it?
Enabling, supporting and encouraging other agencies in the voluntary or statutory sector to adapt their services to meet the needs of an ageing community may be just as effective as planning and delivering a direct service.

Older people with learning disabilities
….were positive, enthusiastic and keen to get involved. They were as varied in their wants, needs and aspirations as other older people.
Resources and publications

Organisations

INTRAN is the multi-agency interpretation and translation service for Norfolk. It commissions four other agencies to provide written translations, telephone interpreting, face-to-face interpreting and lip speaking/British Sign Language interpreting. These agencies are selected to provide the most cost-effective service. INTRAN is non-profit making and exists for its members

www.llsupport.com/intran

The Positive Futures Team is a service for learning disabled people in and around Nottingham. The team provided training and information for staff of Age Concern Nottingham

www.positivefutures.me.uk

A set of 48 slides covering a wide range of information including prejudice, stereotyping, challenging behaviour and inappropriate behaviour, based on the training course, and 5 service leaflets have been translated into an alternative form – available from Carol Wilby, Community Manager

wilby@ageconcernnotts.org.uk

Publications

Turning Point and the Estia Centre (2006) Supporting Complex Needs – A practical guide for support staff working with people with a learning disability who have mental health needs

Valuing People Support Team (2007) Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guide

Report on the work of the Mutual Caring Project – identifying the information and support needs of people with learning difficulties. Detailed questionnaire used in face-to-face discussions.

Contact Eamon McGrath, Community Development Manager

eamon.mcgrath@acnorfolk.org.uk

Older people with learning disabilities and dementia – a good practice guide for health and social care (part of the Let’s Respect toolkit, published by The Care Services Improvement Partnership)

www.olderpeoplesmentalhealth.csip.org.uk/lets-respect.html
Practical help

RESPOND runs a national telephone helpline for older people with learning difficulties and disabilities, their families, carers and professionals. The national helpline provides advice and information on issues related to ageing and learning disability. The helpline is free and open Monday - Friday. Tel: 0808 808 0700

Useful websites

- British Institute of Learning Disabilities [www.bild.org.uk](http://www.bild.org.uk)
- Norah Fry Research Centre. Part of Bristol University’s Department of Mental Health. Particularly interested in evaluation and development for people with learning difficulties [www.bristol.ac.uk/Depts/NorahFry](http://www.bristol.ac.uk/Depts/NorahFry)
- Inspired Services. Provides a one-stop shop for accessible information services [www.inspiredservices.org.uk](http://www.inspiredservices.org.uk)
- Department of Health Learning Disability website [www.dh.gov.uk/learningdisabilities/index.htm](http://www.dh.gov.uk/learningdisabilities/index.htm)
- Foundation for People with Learning Disabilities. Charity researching learning disabilities issues [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)
- MENCAP national learning disability charity [www.mencap.org.uk](http://www.mencap.org.uk)

Pilot project contacts

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Age Concern Norwich: David Fullman, Equality & Diversity Officer  
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How to get further information

Les Bright, independent consultant, undertook the programme evaluation and wrote the evaluation report on which this briefing is based BrightLes@aol.com

The full evaluation report is available on acknowledge.

For further copies of this briefing contact: Sally Steele, Research & Development Unit, Age Concern England. Sallyanne.steele@ace.org.uk 020 8765 7714