

Today and Tomorrow

The Findings of the Growing Older with Learning Disabilities programme

SUMMARY

The Growing Older with Learning Disabilities (GOLD) programme (1998–2002) was set up by the Foundation for People with Learning Disabilities to draw attention to the needs of older people with learning disabilities in the UK. The programme funded and co-ordinated a range of projects to promote greater understanding of the issues of concern to older people themselves and to older family carers. It explored ways in which services can support their needs and aspirations.¹

BACKGROUND

Recent major government policy and strategy reviews in England, Scotland and Wales considered the health and social care needs of older people with learning disabilities and older family carers. The reviews emphasised partnership working and service developments based on the principles of rights, independence, choice and inclusion.^{2,3,4}

These national initiatives will require policy-makers, commissioners and providers to reorganise, reform and develop services to ensure that health and social care services meet the needs of older people with learning disabilities, and that older family carers are supported and helped to plan for the future.

The population of older people with learning disabilities is increasing as a result of a significant increase in the birth rate in the 1950s–1960s. Also, life expectancy continues to increase (particularly for people with mild learning disabilities) and about half can expect an average life span for the population as a whole.⁵

THE RESEARCH

The following major issues were identified:

- the social inclusion of older people with learning disabilities
- people with learning disabilities living with older family carers
- the needs of people who develop dementia, particularly adults with Down's syndrome
- life changes for people with learning disabilities growing older (notably the menopause and terminal illness).

The GOLD programme involved:

- 13 externally funded projects which undertook research, developed innovative ways of meeting needs and produced training resources
- in-house projects including a survey asking older people and family carers about their experiences and views on growing older, a study of older people with learning disabilities in residential services for older people and the GOLD Over 50 Saturday Group

- supporting the development of a broad network of people committed to the well-being of older people with learning disabilities.

The GOLD Over 50 Saturday Group was a reference group for the GOLD Advisory Group and voiced the concerns, views and aspirations of older people.

THE FINDINGS

● Inclusion

Older people want to stay in touch with their friends, make new friends and enjoy regular social and leisure activities, but 'retirement' from day services can result in boredom and isolation. Moving home or becoming more physically frail can also make it difficult to be in touch with friends and get out and about. Two GOLD projects supported people to participate in activities such as allotment keeping, carpet bowls and dancing and keep fit, alongside non-disabled people.

● Health

People with learning disabilities are living longer but have an above-average risk of developing physical and psychological problems as they age. Access to primary care and specialist health services for health promotion, screening, diagnosis and treatment is often patchy and inadequate. A major project on women's experiences of the menopause raised many wider health-related issues. The women wanted more information, support from other women and help with alleviating menopausal symptoms. GPs were not always confident about treating women with learning disabilities and staff wanted more information and guidance to support them. There are also concerns about the health of older family carers.

● Older family carers

GOLD projects on older family carers focused on their current situation and planning for the future, concerns raised in the recent government strategy review for England. They differ from other carers (of parents or partners): the person with learning disabilities is likely to outlive them and they are more likely to be sole carers. Caring has usually been a 'career', ageing can mean smaller networks of family and friends and there has often been limited use of learning disability services. A project on older Pakistani carers also identified specific concerns relating to family size and roles and difficulty accessing culturally appropriate support services. A key finding from all projects was that current needs have to be addressed before planning for the future can be considered. Projects found that individual work and carers groups could both be effective and carers need to be able to choose how they are supported.⁶

● Where people are living

Several projects focused on people's current living arrangements and possible moves triggered by age-related needs (for example, onset of dementia or terminal illness) or the family carer's frailty or death. One project looked at how people can be supported to remain at home in owned or rented property. In house research identified issues of concern. People with learning disabilities moving into older persons' residential and nursing homes were admitted at a younger age than other residents, many lacked regular activities outside the home and had little contact with family or friends. More than a quarter of these older people had moved following closure or redevelopment of their learning disability residential home which suggests a shortage of accommodation to meet their changing age-related needs.⁷

- **Supporting people with Down's syndrome and dementia**

Adults with Down's syndrome are living longer but have a considerably above average risk of developing dementia in their 40s and 50s. Three projects explored ways of improving screening and diagnostic services, and day and residential support and care at all stages of this illness. Flexible and individual packages of care are required in an environment which minimises disruption and disorientation and maximises remaining skills and abilities. One project produced a training resource for staff and carers to meet their need for information and skills development and illustrated booklets for people with learning disabilities.⁸

- **Terminal illness**

Twenty-one case studies of people with learning disabilities who had died and the experiences of those who had cared for them produced important signposts for services to ensure that people are well supported in their terminal illness. Issues identified included:

- prompt diagnosis
- informed choice and decision-making about treatment options
- appropriate transition from curative to palliative care
- effective management of physical and psychological symptoms
- appropriate disclosure with open communication
- collaborative inter-agency working
- support for relatives, care staff and friends before and after the death.

IMPLICATIONS

- Older people should have person-centred plans based on their current needs and choices and their future age-related needs and aspirations.
- The planning and development of learning disability services will need to increase capacity to meet the predicted increase in the ageing population.
- Local registers of people with learning disabilities should be set up and maintained to enable health and local authorities to plan for the future.
- The staffing and physical environment of current learning disability services will need to adapt to meet existing users' future age-related needs.
- Older people with learning disabilities and their carers should be supported in ways which respect their specific religious, cultural and ethnic backgrounds.
- Older people should have access to independent advocacy, particularly if they have no family contact.
- Joint working is crucial. Learning disability services should take the lead in collaborative working, particularly with older people's services.
- Staff working with older people need opportunities to access relevant information, training and skills development.
- Older people must be supported to maintain friendships and relationships, and to access leisure and social activities of their choice.

- Staff in health and learning disability services should ensure that older people can access services which meet their physical and mental health needs and encourage a healthy lifestyle.
- Adults with Down's syndrome need to be able to access screening to detect and treat the early onset of dementia.
- Older people should not be inappropriately placed in residential and nursing homes, but should choose where they live and with whom.
- Practical and emotional support, including provision of information, short-term breaks and support groups, should be routinely offered to older family carers.
- Family carers who are 60 or older should be able to begin planning for the future with the added assurance that support will be offered in an emergency.

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