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Older People with Learning Disabilities: Workforce Issues

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Abstract

The life expectancy of people with learning disabilities has increased substantially. However, services for older people with learning disabilities are provided by different sectors and practitioners (generic health and social care, or specialist learning disability or old age). The literature suggests that practitioners do not feel well equipped to support people with learning disabilities as they grow older and older people's services do not always have the opportunity to share experiences and skills. This paper highlights areas such as dementia support, where the intersection between services is not clear and explores what may help practitioners to meet the needs of people with learning disabilities as they grow older.

Key words: learning disabilities, Down's syndrome, workforce, dementia.
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Introduction

In the last few decades, the life expectancy of people with learning disability has been steadily rising and their health and social care needs are potentially changing. These include individualised responses to the changes associated with growing incidence of age-related dementia, especially among people with Down's Syndrome (the most common cause of learning disabilities, Turk et al, 2001) at younger ages than the general population (Whitehouse et al, 2000). In addition, people with learning disabilities who are growing older and their carers as well as service providers, are not yet sure what services are most effective or should be developed. These uncertainties may lead to older people with learning disabilities being misplaced, underserved, and with an array of un-met needs.

In this article we focus on the 'grey areas', where the intersections between services are not clear. We will explore what may make the skills and experience of practitioners in older people's services more accessible to people with learning disabilities. Our discussion will focus on older people with learning disabilities, in particular those with Down's Syndrome, among whom physical health problems are likely to be common (such as heart problems). We argue that one key building block for an effective service for older adults with learning disability is a workforce with skills, knowledge and values that will provide high quality support and enable people to maintain their well being as much as possible.

The White Paper *Valuing People* states that service developments should 'enable people with learning disabilities to access a health service designed around their individual needs' (Department of Health, 2001). But what is the best way to address wider and inter-related needs of later life? Who should deliver support and what sort

of training is needed? Will integration between health, social care and housing support services meet the needs of older people with learning disabilities? At the least, how can practitioners from different service worlds be aware of the support others offer and how to build on it? The setting up of a national workforce group by the Valuing People Support Team in summer 2004 means there is scope to debate these issues.

Health in Later Life

People with learning disabilities are living longer (to 50 to 55 years on average) and some of them are living to ages of 70 or older (Yang et al, 2002). In the UK and other developed countries, there has been a steady increase in life expectancy for people with Down's Syndrome, from 9 years in 1929, 12 years in 1949, while in 1997 eight out of ten reached the age of 50 years and some reach their 60's and 70's (Kerr, 1997). Cooper (1997) observes that now more people are aged 40 years or over with learning disabilities than children with learning disabilities. However, their life expectancy is still significantly lower than that of the general population (75 for men and 80 for women in the UK, ONS, 2001). There is also considerable evidence of poor health among people with learning disabilities. For example, (in)activity levels amongst adults living in a variety of settings in UK are equivalent to those of non-disabled people aged over 75. This means that people with learning disabilities face serious associated health risks, and as with the general population, smoking and drinking alcohol may have long-term effects. Rates of obesity are significantly higher amongst women with learning disabilities compared to women in the general population (Emerson et al, 1999). Moreover, although people with learning disabilities have high levels of unrecognised illness, often they have poor access to health promotion (Band, 1998) and some is of limited extent (as one study notes this may centre on sex and cooking, Jobling 2001). For support staff this means that there may be particular needs to encourage people to attend regular check-ups, or with understanding and adoption of health promotion messages.

Across the life course a number of other factors are commonly associated with Down's Syndrome, although individuals differ.

- Some of today's older generation with Down's syndrome may have had restricted opportunities for education and participation in ordinary life settings. They may not be familiar with making plans and choices about social support and community activities. This points to the importance of support staff being able to help people with Down's syndrome set out their needs and preferences for the future.
- Some people with learning disabilities now have considerable experience in systems such as direct payments, care planning, selecting staff and consultation and involvement. This may contrast to some practices in older people's services.
- Support with healthy eating, physical activities and regular check ups among people with Down's Syndrome as they grow older may be important, particularly as people retire from work.
- Mild to moderate hearing loss is more common in people who have Down's Syndrome, as are visual problems such as squints and long- and short-sightedness. Such problems may worsen in later life but may be under-recognised.

- There is an increased chance of developing Alzheimer's disease in middle-age, 20-30 years earlier than the general population, and the effects may be slow to determine or can be confused with other problems. Those supporting people with Down's syndrome need to acquire knowledge of signs associated with dementia to refer people for assessment and possible treatment, and to provide timely support. This includes thinking about how to tell people their diagnosis and how to explain what is happening, to fellow residents, for example, if this is agreed.

Pulling this together to consider the health and support needs of people with learning disabilities, and in particular those with Down's syndrome, suggests that increasing age results in a greater likelihood of additional physical and mental health problems in some areas. However, reduced life expectancy of those with most severe disabilities may mean that 'there is convergence in later life between people with learning disabilities and those without' (Holland 2000 p 26). We do not know much about the 'positive' health behaviours that may protect some people from illness or disability in later life. But in one area we have greater evidence, although many family carers and practitioners remain unaware of the risk of dementia faced by people with Down's Syndrome, or feel ill-equipped to recognise and meet their needs (Oliver and Holland, 1986, Wilkinson and Janicki, 2002). The dementia care workforce has such expertise, mainly in respect of people who are much older and who may not have had prior disabilities. Can this experience be harnessed?

Who Provides Support?

While people with learning disabilities have on average higher physical and mental health needs than the general population, in fact they visit their GP less often and use fewer preventive services than the average population (Parrish, 1998). Older people with learning disabilities are usually described in the literature as an underserved group, especially in regards to health care (Band, 1998). For this reason *Valuing People* has made health improvement and monitoring one of its objectives.

People with learning disabilities, including those with dementia, live in a variety of settings; independently, with their families, in group homes, in care homes and others. The needs of family carers as they grow old have been the subject of specific follow up and local surveys. The Foundation for People with Learning Disabilities is currently providing a supportive network for practitioners and policy makers in this area (<http://www.learningdisabilities.org.uk/page.cfm?pagecode=PIOF>) as part of its Older Family Carers Initiative.

In the UK, almost two-thirds of adults with learning disabilities live with their families (DoH, 2001). Most other adults with learning disabilities, 37 percent, live in some kind of communal housing, a percentage that increases to 70 percent among people over 55 years. How do such services meet the needs of older people with learning disabilities? The Department of Health recognises that 'high health care needs can be met in non-institutionalised settings if the issues relating to staff competence and skills are addressed' (DoH, 1998). However, many examples exist (Thompson and Wright, 2001) of people being forced to move away from all that was familiar because of predictable age related changes including declining mobility or the onset of dementia. Thompson and Wright (2001) also observe that the moves of

people with learning disabilities into residential services for older people were, in many cases, due to the death or illness of family carers even though the person's age and levels of disability could be far below the threshold for other disabled people (DoH, 2001; Scottish Executive, 2000).

Support Settings

Within residential services for older people, recent research (Bland et al, 2003), which explored the quality of services for people with learning disabilities, found a complex relationship between quality and cost. Staff working in services for older people believed that older people with learning disabilities would have a better quality of life in learning disability services. These concerns are mainly to do with length of stay, training needs of staff, lack of activities and opportunities for older people with learning disabilities, and difficulties in integration.

Foremost of these, as the Growing Older with Learning Disability (GOLD) project argues, is the 'misplacement' of people with learning disabilities in care homes for older people (Thompson and Wright, 2001). As noted earlier, people with learning disabilities have often been moved to older people's residential services, not because of their own age related disabilities but for different and questionable reasons. Hospital closure resulted in many people being 'resettled' directly into older people's services. Examples of this were found in the GOLD research, but there were also instances where the later reorganisation of community facilities had led directly to people being 'passed over' to older people's services. It was not uncommon for people who were moved under these circumstances to be much younger than other residents.

Due to the relatively young age many older people with learning disabilities enter older people's services, they are more likely to reside in older people's care homes for longer than other people. This is particularly the case for individuals who are moved to care homes because of changes in their previous support networks rather than because of their own disability. This means they have an unusually long experience of a way of life mostly reserved for the final stages of people's lives. Recent research highlights the limited choices of people with learning disabilities who developed dementia about their support (Stalker and Hunter, 1999; Kerr et al, 2002).

But service providers too appear to find this state of affairs problematic. Care homes often have trouble in staff recruitment and retention, and are struggling to meet targets for training. Meeting standards for the care of people with learning disabilities places further challenges if a home is primarily used to supporting very elderly people. It is not clear what is the best training for staff to meet the inter-related, and often complex, needs of older people with learning disabilities. Experience may be limited, and links with learning disability services to gain support may be under-developed.

The Future for Workforce Planning

The commissioning of services to meet the individual needs people with learning disabilities as they grow older is a key task for Partnership Boards. This should include attention to the workforce supporting older people with learning disabilities. In this section, we focus on people with learning disabilities who develop dementia as

an illustration of the potential for building common ground between learning disability and older people's practitioners.

Wilkinson and Janicki (2002) observe that several staffing issues require consideration including specifying clear job descriptions for staff from different agencies (health and social care). Equally important is co-ordinating or building common platforms between different types of staff. Box 1 and 2 summarise what staff in each setting need to know about the speciality of the other, focusing on dementia rather than ageing in general. Similar discussions could be held about other long-term conditions such as diabetes or coronary heart disease.

Box 1: What Staff in learning disability services need to know about dementia:

- Ageing process and pattern recognition
- Resources/services/support for themselves
- Local 'map' of provision
- Rationale for psychosocial interventions e.g. reminiscence
- Possible behavioural changes
- Legal issues
- Examples of good practice
- Opportunities to observe high quality support

As with other mental health problems for people with learning disabilities, and for older people in general, it can be very difficult to make a diagnosis of dementia. This is particularly true if people do not know the person well. Currently there is no standardised single assessment process to identify the onset of dementia among people with learning disabilities (Whitehouse et al, 2000). Therefore, recognition of dementia, followed by providing adequate support, relies mainly on families' and staff observations (Oliver 1999; Deb, 2003).

Typically, it is difficult to know if someone has lost previous skills if no one is familiar with the skills that they had previously. On the other hand, changes in people with learning disabilities, especially those with Down's syndrome, can be too easily be put down to dementia without investigating other possible causes. The tasks then are at several levels. The first is knowledge acquisition. People who support older people with learning disabilities, whether social workers, social care, health or housing staff, or family carers, need to know more about:

- Ageing, dementia and learning disabilities health related needs. While many will know, some may need to be told about the possible signs of early onset of dementia and what to do if these are suspected. Their knowledge of the person will help to construct a history that medical professionals will be able to use in distinguishing between such signs and other non-dementia problems. They will also be able to transfer, or at least record, their knowledge regarding any communication difficulties the person they support may have, and can suggest the most effective communication methods to other professionals.
- Training and understanding will enable them to plan and anticipate changes when supporting people with learning disabilities and will help prevent crisis or to respond to it with some prior thought and strategies.

- Everyone needs to know who to contact and how to seek additional support for themselves and service users (e.g. through advocacy networks).
- Likewise, everyone needs to know when and how to communicate with other services, especially community and voluntary groups.

Both learning disability services' staff and dementia support staff are expected to support older people with learning disabilities with dementia at different, and sometimes similar, points of time. Box 2 summarises what dementia staff may need to know in order to offer advice, support and when taking on responsibilities for service planning or provision. Other tasks will relate to collaboration or integration around specific care settings and specific issues. Advocacy services, for example, may be specific to a 'client group' but have much to learn from each other.

Box 2: What dementia support staff need to know about learning disabilities in general and in particular:

- Its impact on a person's life (e.g. communication style)
- Resources/services/support for themselves
- Local service 'map' and contacts
- Impact on assessment
- A person's past networks/lifestyle/preferences/culture and beliefs
- Examples of good practice

Emergent Issues

People with learning disabilities from ethnic minority groups may be more vulnerable to social exclusion and face a wider set of barriers to access services. Research indicates that older people from ethnic minority groups who develop dementia find that some services are inappropriate and hard to access (Boneham et al, 1997; Patel et al, 1998; Bowes and Wilkinson, 2003). From the US, there is evidence that people with learning disabilities from ethnic minorities who develop dementia may face even higher obstacles and have more unmet needs (Janicki, 2001). Service providers need to consider how to make services more accessible to older people with learning disabilities from ethnic minorities. Understanding and appreciating the impact of social, cultural and environmental factors are important in recognising signs of dementia and catering for subsequent needs. Overall, research on the particular needs of people with learning disabilities who develop dementia is limited in the UK (Mental Health Foundation, 2002; Wilkinson et al, 2003). Examples of good practice are still to be developed and tested. This means that support staff need to collaborate with older people with learning disabilities and their carers to develop culturally sensitive interventions and support systems for all citizens.

Ways Forward – Service Dialogue

Wilkinson and her colleagues' (2003) recent study of dementia and learning disability services has brought new service demands onto the agenda. They make the case for services to employ more night-staff, for practitioners to develop experience in communicating to other service users that a person is developing a dementia, and for services to provide support to staff. Such findings confirm the need for a workforce that is flexible, that can work with individuals and with groups, with older people and with people who are growing older, and that will work best if itself is respected and valued.

Integrated services have the potential to make the most of staff by acknowledging and building on their transferable experience and expertise. Currently integration is generally seen as cross-sector (health and social care). The needs of people with learning disabilities who develop dementia suggest that integrated services can also be a way of making the most of experience and expertise *within* each sector, such as that held by specialist learning disability practitioners and by specialist dementia support staff. In the absence of integration, greater dialogue within services and practitioners may be valuable. In this way, we may help to avoid one-way valves between services and settings, and develop skills and experience among practitioners.

Box 3: Potential outcomes of service dialogue:

- Better planning/less crisis?
- Anticipation of change?
- Tailored responses?
- Greater ability to modify environment?
- Enhanced communication between services?
- More confident, skilled staff?
- Better quality of life?
- Better support for families?

Box 3 presents possible outcomes of training, networking and shared care between sectors and local community services with their different practitioners. Support staff may be able to plan better and thus prevent unnecessarily crises. They should be able to anticipate changes and be more confident in responding to them or knowing who to ask for advice. Such outcomes need to be evaluated through participatory research where possible.

This article has focused on dementia as an example of a disability that may present particular challenges to services supporting the growing number of older people with learning disabilities. It has suggested that front-line practice may be enriched through learning more of each other's skills, experience, networks, and knowledge. A suggested set of outcomes has been established here: this needs to be debated with people with learning disabilities, their families and other supports. Evidence now exists that researchers and services are recognising this area as one where closer working together may have many benefits to individuals and to practitioners alike.

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