

Policy into Practice

Growing Older with a Learning Disability

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Introduction

This paper identifies the major support needs for older people with learning disabilities. As a group they are simultaneously the focus of two recent policy documents in England: the *National Service Framework for Older People (NSF)* and *Valuing People - A new strategy for learning disability in the 21st Century (VP)*, (Department of Health, 2001a, 2001b). The potential impact of these policy initiatives on the lives of older people with learning disabilities now, as well as future generations of older people with learning disabilities, will be discussed. It will be argued that they provide encouraging opportunities for services to come together to provide the kinds of support older people with learning disabilities and their family carers are seeking. That said, unless specific attention is given to the needs of this group as local services are developed, particularly as *Fair Access to Care Services (FACS)* (Department of Health, 2003a) is implemented, it will be difficult to give people with learning disabilities and their families confidence in the future.

The Policy Context

Older people with learning disabilities have recently been the focus of significant research and discussion. For example, internationally, ageing is one of the most active interest groups of the Association of the Scientific Study of Intellectual Disability (IASSID). In the UK the Foundation for People with Learning Disabilities recently undertook a major programme of work in this area (see Wertheimer, 2002).

One possible explanation for this interest is a response to increasing numbers of people with learning disabilities over a certain age (e.g. Carter and Jancar, 1983). However, any increase is difficult to confirm - not least because of the lack of reliable registers in the UK (see Emerson et al,

2001). One significant change is the increase in life expectancy of people with Down's syndrome. In the early 1900s this was less than 10 years (Penrose, 1949) but now half of people with Down's syndrome can expect to survive into their 50s with some reaching their 60s and 70s (Malone, 1988). For those people with learning disabilities without Down's syndrome a recent Californian study found life expectancy to be between 70 and 74 years (Stauss and Eyman, 1996).

Table 1 provides a snapshot of the age profile of people with learning disabilities taken from the Sheffield Case Register in 2002 (figures courteously of the Sheffield Case Register). At this time the register had information about 2,645 people with learning disabilities from a population of 538,000 and is regarded as one of the most reliable registers in England. It shows that the life-expectancy of these people with learning disabilities falls short of general life expectancy figures in the UK which currently stand as 75 for men and 80 for women (Office of National Statistics, 2001). This is consistent with the Department of Health's own evidence of avoidable illness and premature death among people with learning disability (2001b:19).

However, the current challenge of providing support to older people with learning disabilities is less about any increase in numbers than changing service arrangements being able to meet their needs. The last learning disability White Paper *Better Services for the Mentally Handicapped* (Department of Health, 1971) was the impetus to close many of the large NHS institutions which were home to most people with learning disabilities living outside of the family home. Government figures show that the number of people with learning disabilities living in NHS facilities has reduced from 58,850 in 1969 to just under 10,000 in 2000. Over the same time the number of people living in residential care places in the community has risen from 4,900 to 53,400 (Department of

	0-9	10-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90-99
With Down's syndrome	25	47	40	68	71	31	6			
Without Down's syndrome	310	385	302	416	372	272	178	86	33	6

Health, 2001b: 17). It was both normal and expected that people with learning disabilities grew old and died within the large institutions – evidenced by the graveyards commonly attached to these. The demise of these settings over a relatively short time has produced a much more complex and uncertain picture of later life for people with learning disabilities.

Below the difficulties for older people with learning disabilities to firstly access good support now and secondly to have confidence that it will remain in place and able to respond positively to age related needs will be explored. As will be seen, people with learning difficulties can face age related challenges much earlier than the general population so it is unhelpful to set some fixed age at which point *older* starts.

Valuing People - a new strategy for learning disability in the 21st Century

VP sets out ‘how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities’ (Department of Health, 2001b: 2). It identifies many deficits of existing provision, including poor health care, insufficient support for family carers, and a shortage in both availability and choice of housing outside the family home. The strategy embraces partnership working through the creation of local Learning Disability Partnership Boards whose members are to include health, social services, education, housing and the voluntary sector, together with representation from both people with learning disabilities and family carers. The Partnership Boards have been tasked with a set of timed objectives. These include ensuring *person-centred planning* is in place, undertaking a process of review and development of day opportunities, producing an employment and housing strategy, and closing the remaining long-stay hospitals.

Aside from the requirements to complete the closure of hospitals and to ensure a proportion of staff have received appropriate training, local authorities have huge flexibility about the content of their plans and hence the volume and range of services they provide. So while ‘the Government

is committed to tackling the postcode lottery’ (Department of Health, 2001b: 21) of service delivery, it is difficult to see how this will be achieved in such an open policy framework. Further with only an additional 1% of annual expenditure on learning disability services (Department of Health, 2001b: 18 and 112) being committed to support the implementation of the policy, there are clearly enormous challenges in addressing the deficits identified by the Government itself.

National Service Framework for Older People

This *NSF* was also published in the same month as *VP*. It was the third in a series of *NSF*'s which aim to ‘improve services through setting national standards to drive up quality and tackle existing variations in care’ (Department of Health, 2001a: 8). One of its key aims is to root out age discrimination in NHS or social care services. It has many similarities in its nature to *VP*, for example, milestones have been set, planning needs to be inclusive of a wide range of organisations and local authorities are encouraged to use the flexibilities introduced in the Health Act (1999) for developing collaboration between health and social services. Other common features include a commitment to involving service users and their family carers and the establishment of a national Implementation Team and a Taskforce to oversee delivery. There are, however, three key differences:

1. The *NSF* is primarily concerned with the healthcare of older people, whereas in *VP* health is just one of a number of concerns which are addressed. Because of this, it is not surprising that ultimate responsibility for the delivery of the *NSF* at a local level rests with the NHS whereas the chief executives of local councils are responsible for establishing the partnership boards required by *VP*.
2. There is much greater specificity about the services that should be available locally within the *NSF*. Examples include: a single assessment process for health and social care, specific figures for the number of additional intermediate care beds and for people receiving intermediate care services which promote

rehabilitation, and year on year improvements of flu immunisation, smoking cessation and blood pressure management. Associated with these much clearer service expectations is a more demanding programme of performance monitoring by Strategic Health Authorities, the Social Service Inspectorate and the Commission for Health Improvement.

3. Although the remit of the *NSF* was to set it in the 'context of available resources' (Department of Health, 2001a: 9), the *NSF* will benefit from an extra £1.4 billion annually by 2004 under the NHS Plan (Department of Health, 2000a). Most of this additional money is targeted at the development of intermediate care services (p.136). This increase represents over 9 per cent of the total health and social care spending on people over 65 in 1999/2000 compared to the more limited 1 per cent additional funding which accompanied *VP*.

Accessing Support

Older people with learning disabilities are largely living in the family home, in residential services for people with learning disabilities or in residential services for older people. With age there is a progression from the family home to residential services, although about a third of people with learning disabilities over 55 continue to live with their families (Kavanagh and O'piti, 1999). One third of people with learning disabilities living in the family home are thought to be living with a family carer over the age of 70 (Department of Health, 2001b: 56). Therefore for many older people with learning disabilities living in their family home, getting the right support involves their relative simultaneously getting support both as a carer and as an older person.

There is considerable evidence to show that many people with learning disabilities living with older family carers have been neglected. Indeed it is suggested that up to a quarter of people with learning disabilities do not become known to services until their relative is physically unable to continue caring because of their own ageing (Department of Health, 2001b: 57). In particular, key issues include (Walker and Walker, 1998):

- Mutual dependant relationships between older carers and the person they care for, so that the needs of either cannot be separated from the other.
- Either person's ageing will increase the demands of caring for each other. Similarly, ageing and death will cumulatively undermine any support which is available from spouses, other relatives and friends. This can lead to a very isolated existence.
- Poor information about and a suspicion of services often based on bad experiences in the past.
- A huge worry about what will happen in the future but few resources to make any arrangements.

VP pays special attention to people with learning disabilities living with family carers over 70. It encourages local authorities to identify these families and to make them a priority for the implementation of person-centred planning. Also some of the limited funding which accompanied the White Paper has been earmarked for 'developing supported living approaches' for those living with older family carers. The idea being to keep people out of residential care and to give them the opportunity to continue living in the family own home or to move to what might be a more appropriate property (with or without friends) when their family carers become unable to continue to provide support.

These families may also benefit from the provisions of the Carers Strategy (Department of Health, 1999), in particular accessing breaks and other carer services so that they can continue living together as long as is desired. To this end *VP* said that local authorities would be encouraged through the 2001/2002 guidance for the Carers Grant to target older family carers (Department of Health, 2001b: 57), but such advice was not forthcoming.

It is also unfortunate that the *NSF* does not explicitly recognise the complexity of caring relationships that may exist amongst older people. For example, the single assessment process does recommend an exploration of 'caring arrangements' but only encourages the assessor to find out whether 'family members or friends are

acting as carers' (p.33). This will mean that their caring responsibilities for the person with learning disabilities may be overlooked if, for example, the older family carer is admitted to hospital.

Outside the family home it is known that people with learning disabilities receive very different levels of support. There is strong evidence that community based support is an improvement on institutional care (Emerson and Hatton, 1994). However, residential support in the community can vary greatly in quality (Felce et al, 1999) and many older people with learning disabilities are living elsewhere – either amongst the remaining occupants of the institutions (Department of Health 2001b: 103) or in residential services for older people (Thompson, 2002a, 2002b).

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Whilst the placement of older people with learning disabilities in residential services for older people might be offered as positive inclusion, it is important that these are exactly the services that the NSF is trying to keep all older people out of. Further it is at odds with VP's desire to avoid large shared housing schemes. The experiences of people with learning disabilities in these services also show there is little to commend them. These include very few opportunities for structured activity either within the home or outside, having staff untrained to work with people with learning disabilities and little contact with learning disability professions (Thompson, 2002a, 2002b). A crucial factor in understanding this apparent poor quality of life is that residential and nursing homes for older people cost about only a third of what is considered to be good quality community support for people with learning disabilities (Thompson, 2002a, 2002b).

Maintaining Support

The philosophy of *VP* is to continually strive to improve the lives of people with learning disabilities through better health care, day opportunities, accommodation choices and support for family carers. This aspiration is clearly relevant for older people with learning disabilities; however at the same time there is a challenge to ensure that their lives are not unnecessarily compromised because of age. This is the more restricted philosophy of the *NSF*.

Below are the common age related *critical incidents* that occur in the lives of people with learning disabilities which bring with them a risk of an undue decline in their quality of life because of poor support. Alternatively they can be seen as key opportunities for services to demonstrate their commitment to person-centred planning and care:

Having birthdays: It is not surprising with the *NSF*'s acknowledgement of age discrimination to find evidence of age discrimination in services for people with learning disabilities. Examples include younger people resettled from hospitals being found to have better access to day services than older people (Walker et al, 1996) and the inclusion of relatively young people with learning disabilities in residential services for older people (Thompson, 2002a). Furthermore, some day services have been found to operate retirement policies which are not about responding to changing need or wishes, but which keep people at home with nothing to do and away from longstanding friends (Wertheimer, 2002).

Moving from the family home: For older people with learning disabilities a move from the family home is particularly critical as at the same time they may have to cope with the poor health or death of their family carer. Clearly planning for such a time is desired to avoid what could be inappropriate placements - many of the people found in older people's homes have been placed as a consequence of the death of a relative (Thompson, 2002a). Any accommodation that is not close by is unlikely to be desirable as it will undermine opportunities for continued contact with family or friends who may find it particularly difficult to travel because of their own age. It may also mean the end of accessing a familiar day service or social club and so losing other irreplaceable friendships. Few other people in this country would be expected to deal with such compounded trauma.

Reorganisation or closure of services: The agenda to improve services inevitably mean changes. However, there is evidence that older people with learning disabilities are particularly vulnerable to having to pay the price for change. For example, as institutions closed many older people with learning disabilities have not had the opportunity to

gain the benefits of living in the community - very often being moved instead to older people's residential services (SEHD, 2000; Thompson, 2002a). Similarly a group of older people with learning disabilities living in a large hostel were all displaced to an older people's home to allow for more individualised living arrangements for the younger people living there (Thompson, 2002b).

The modernisation of day services will expose older people to similar risks. One concern is that the emphasis on employment and thus assumptions of who is of *working age* may shift resources away from older people accessing more traditional support. It is also the case that older people can find it particularly difficult to cope with change and may opt out of new service arrangements precisely because of this. Similarly, for those living with older family carers there is a danger that their family carers will be unable to meet the pressures placed on them by changes in provision (e.g. coping with new transport arrangements).

Declining mobility: Declining mobility is a challenge for many to maintain their independence. People with learning disabilities may be particularly susceptible because of extremely poor levels of physical activity and high rates of obesity amongst women (Emerson et al, 1999). The strengthening of intermediate care may help more people with learning disabilities and/or their family carers to access timely housing adaptations and other home support and so avoid unnecessary moves.

The situation is more complex for people in registered care where some providers wishing to make adaptations have found these to be unacceptable to local inspection teams. It is too soon to say how flexible and helpful the National Care Standards Commission will be in such circumstances when monitoring both the standards for adult and older adult services.

Forward-looking services have started to plan for this predictable age related change by ensuring that people with learning disabilities at particular risk are housed in either ground floor or easily adaptable accommodation (Dodd and Turk, 2002). Clearly the physical accessibility of services needs to go beyond where people live to include all day and social opportunities.

Dementia and other terminal illnesses: People with Down's syndrome experience a very high risk of dementia and do so at an earlier age than the general population. For example, Holland et al (1996) found prevalence rates of zero per cent, 3.4 per cent and 26 per cent amongst the 30-39, 40-49 and 50-59 age groups respectively. Services respond variously to this challenge from working to ensure that the person can continue to live in familiar surroundings with appropriate support to enforcing a move to an older person's residential service which is ill equipped to meet their needs. The *NSF* requires the development of specialist mental health teams who will be expected to work alongside learning disability services in such cases, irrespective of the age of the person with Down's syndrome (p.90).

Services are also greatly challenged when people with learning disabilities acquire other terminal illness and are in need of palliative care. One study found extreme variations in the care provided, with some learning disability services finding it very difficult to gain appropriate support from mainstream services on critical issues like pain relief (Brown et al, 2002). Also significant was absence of hospice use, which suggests that people with learning disabilities are not accessing the full range of supports which are available to other people with a terminal illness. To try to improve the support people with learning disabilities receive when they have a terminal illness and to build bridges with the field of palliative care a network of interested individuals has been formed (1).

Improvements on the poor record of diagnosis and treatment of serious illness among people with learning disabilities are clearly required (Department of Health, 2001b, p60). These may be achieved through the development of individual Health Action Plans set out in *VP*, the commitment to improve health care in the *NSF* and better access to cancer screening set out in *The NHS Cancer Plan* (Department of Health, 2000b).

Loss of family involvement: For many people with learning disabilities, getting older is associated with reduced contact with family and other individuals who provide informal support - these could be neighbours or other longstanding family friends. A range of factors can contribute to this decline, including deaths, people moving and

contact being made harder because of ageing. It is important to recognise that whilst some of this loss of contact may be inevitable, much is dependent on service interventions (for example, where people are moved, the support they have to stay in touch and how welcome relatives and other friends are made in services).

The impact of loss of contact is twofold. Firstly the obvious risks of loneliness and depression. Secondly continued contact with family and friends is a important safeguard against neglect and abuse within the service system (Bigby, 2000). This study showed how having someone *looking out* for the person could both prevent them entering and rescue them from inappropriate placements. It also showed that this important role was often passed on through generations (e.g. from the person's mother, to their sister, to their niece), but was also very vulnerable to being weakened or lost over time.

Both the *NSF* and *VP* recognise the importance of the involvement of family carers, however neither has much to say about supporting people in this vital role if the older person with learning disabilities is not living with them. Indeed the emphasis on developing citizen advocacy services in *VP* suggests that people's natural advocates may be sidelined.

Fair Access to Care Services

Oxfordshire is a rare example where a local strategy for older people with learning disabilities has been developed (see Wertheimer, 2002: 77). The key principles aim to enable people to remain in their own homes, to keep active and to be involved in their local communities. It was decided that the best way to achieve this was for learning disability services to lead on assessment, care managing and commissioning though accessing older people services where appropriate. This makes sense in terms of the broader philosophical underpinning of *VP* highlighted above.

One impact of closer collaboration between learning disability services and older people's services is that different service expectations become apparent. For example, older people in residential care are commonly denied access to day

opportunities away from the home because they are considered to be already receiving 24 hour care. However, in learning disabilities the life-enhancing opportunities of, for example, access to education and employment are fundamental aspects of *VP*.

The *NSF* notes that 'in some localities the eligibility criteria for non-residential services mean older people have to demonstrate higher needs to qualify for services compared to younger adults'(p.17). As a result, the *NSF* requires local councils to review their eligibility criteria for adult social care to ensure that they do not discriminate against older people. Optimistically this may improve the support available for all older people (including people with learning disabilities) - for example preventing their 'retirement' from day services. However, there is a clear danger of a levelling down of services which may undermine the vision of *VP* for people with learning disabilities.

This risk will be compounded as *Fair Access to Care Services* (Department of Health, 2003a, 2003b) is implemented. FACS sets a common *framework* for the provision of social care for adults of any age and reiterates the commitment to rooting out age discrimination contained in the *NSF*. For example, local authorities will be expected to 'justify commissioning or providing services that, for example, separate older users from other adults' (p.6). So while both *NSF* and *VP* seek to end the postcode lottery of service provision, FACS undermines this by allowing local authorities to provide different services to people with similar needs. More remarkably, local authorities can set their own eligibility criteria based on their available resources so that in some areas a person with a particular need will receive a service and in another they will not.

Conclusion

One way of picturing the availability of support to people with learning disabilities as they grow older is to imagine them trying to climb an escalator which is going the other way. They are unlikely to get to the top (which would represent a secure future). Instead, it will always be a struggle to keep up and this gets harder with age. Many will drop to the bottom, which could mean spending

many years isolated in a residential home for older people or having their healthcare needs neglected.

Because people with learning disabilities are largely lifelong users of services there is a need to always consider how service interventions will impact on people's lives in the short and long-term. In the short-term, this might mean ensuring that people are accessing services which could respond well to, for example, a decline in mobility or dementia. For the long-term, services would be wise to do all they can to support and develop people's family and other relationships. For these are the people who are most likely to be there for the person in years to come: both as important relationships to guard against loneliness in old age, but also fighting to ensure they get the best – and not the worst – of the service system, whatever it may look like in the future.

1. For more information about the Palliative Care Network contact linda.mcenhill@st-nicholas-hospice.org.uk

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