

Chapter 8:

Older People with a Learning Disability

Overview

The number of older people is increasing across most developed countries. Over the last 70-80 years the number of people in England for example over age 60 has doubled, and by 2001 over one fifth of the population was over 60 (Scott, et al. 2003). Similar data is not available for Northern Ireland but it is probably not dissimilar.

Life longevity is also increasing with many people now living into their 80s and beyond. The National Service Framework for Older People (Department of Health, 2001) predicts that in the 30-year period (1995-2025) the number of people living to 90 years and beyond will double. This trend, which is due to advances in medical science and social improvements, is also evident in the people with a learning disability (WHO, 2000).

The WHO (1999) views the need for adequate caring services for the ageing population as a crucial matter. As people live longer it is expected that they will become more vulnerable to health problems. However, people with a learning disability are at particular risk (WHO, 2000). The WHO (2000) state:

'In many nations, older adults with severe and profound impairments are disregarded or institutionalized. Housing is often inadequate and health provision neglected. Older adults with mild impairments are often marginalized and not provided with minimal supports needed to be productive members of their societies.'

This review is structured into four Sections.

Section 1 defines old age and the impact ageing has on people with a learning disability in particular.

Section 2 examines the social implications of growing older.

Section 3 reviews information gathered in Northern Ireland.

Section 4 summarises the implications and recommendations for services in meeting the needs of this growing population.

Section 1: Definitions and Impact of Ageing

Growing old is a natural process for everyone and it may seem quite straightforward to define old age. However, a number of key issues do need to be considered. First, the age when one is considered old is linked to the social mores in a particular society. A general guideline might be that the onset of old age is demarcated by when one retires from one's occupation i.e. between 60-65 years in our society. But, this is now becoming more blurred with some people retiring early, and others taking up second careers post retirement. Many people continue to lead full and active lives well beyond the age of 65 years. Secondly, old age may be defined in physical terms i.e. when the biological changes of increased age begin to limit a person's capacity. Finally, old age is psychologically determined. One person may be very happy in their advanced age, while another may go through what can be almost a grief reaction, with a sense of feeling undervalued, worthless and segregated. It may therefore be better to view old age as a state of mind (Ward, 2000).

People with a learning disability

If old age is determined by physical, social and psychological factors, as stated above, the population of people with a learning disability may not 'fit' well into traditional definitions of old age.

If old age is socially constructed this may have little use in determination of when it begins in this population as they are often set aside as a subculture within the society to which they belong. Individuals with a learning disability are restricted socially and have limited social networks (Thorpe, et al. 2000).

The biological aspects of ageing may differ for people with a learning disability in a number of respects. For example, some people such as people with Down's syndrome show signs of ageing in their 30s (Zigman, et al. 2002) ; and life longevity tends to be reduced for people with severe and profound disabilities (Holland 2000; Rice and Robb 2004). Although, some would argue such decline should be kept separate from reduced function as a result of 'normal' ageing (Thorpe et al, 2000). Thorpe et al suggest most adults with a learning disability who live past the third decade are likely to live into old age.

There is limited evidence on how well these people cope psychologically with ageing. It could be that due to cognitive limitations some people find difficulty comprehending the ageing process. This is added to as many individuals with a learning disability are prevented from experiencing normal life events. Thorpe et al (2000) cite acceptance of mortality (an integral aspect of ageing for everyone) to highlight this. They use the example of how people with a learning disability may be hindered in the acceptance of mortality as they are frequently not exposed to rituals such as funerals in an attempt to protect the person from unpleasant events. Such actions may well be doing the individual more harm than good.

Therefore, the social, psychological and biological aspects of aging that everyone encounters may be quite different for many people with a learning disability. It may be more informative and meaningful to identify how this group are affected by ageing than to dwell unnecessarily on how old age is defined.

Impacts of ageing on people with a learning disability

The effects of ageing do eventually impact on everyone. However, for people with a learning disability there are significant differences in relation to the onset of age related difficulties, and there are some problems that are specific to this client group.

Dementia

A number of different types of dementia exist but the most significant and prevalent is Alzheimer's disease. The neurological effects of this disorder are devastating for the person who develops it and for his/her family. It leads to a deterioration in function in virtually all aspects of life, a disintegration of the affected person's personality and eventually death. There is an abundance of research evidence indicating that people with Down's syndrome exhibit neurological changes resulting from Alzheimer's type dementia at a much younger age than others, and in addition virtually all people with Down syndrome who live long enough will develop this type of dementia (Dalton and Janicki, 1999). Table 1 illustrates the percentage of people with Down syndrome with dementia for various age bands. This can be compared with the general population where it is estimated that around 5% of people over 65 years will have dementia, although this percentage increases with advancing age.

Research has found that dementia leads to carers spending much more time in the undertaking of caregiving roles, and the nature of care changes to such aspects as:

- Supervision, or undertaking for the person, activities of living
- Having to respond to behavioural problems
- Much more close attention to safety aspects
- Disruptions to normal daily life patterns e.g. night-time wakening

(Moss and Patel 1997; Martin, et al. 2000; Oliver, et al. 2000; McCarron, et al. 2002;)

Table 1: Percentage of people with Down's syndrome affected with Alzheimer's Disease (McQuillan, Kalsy et al. 2003)

Age in years	Rate %
30-39	0-10%
40-49	10-30%
50-59	20-55%
60-69	30-75%

Health and Sensory Decline

Although increased longevity is positive it does bring with it inherent needs. It is inevitable that as people live longer they are more likely to become exposed to and develop older-age related health problems (Evenhuis, et al. 2001). These health problems are similar to those experienced by other older people in society (Janicki, et al. 2002). However, people with a learning disability may develop what is known as 'syndrome-specific' conditions, see Table 2 for an example of some such conditions.

Table 2: An example of syndrome-specific health problems

Syndrome	Syndrome-specific condition	Authors
Down's	Congenital heart defects	Pueschel & Pueschel (1992)
	Gastrointestinal problems	Pueschel & Pueschel (1992)
	Visual and hearing disorders (related to old age)	McVicker, et al. (1994)
	Infections	Marino & Pueschel (1996)
	Decreased longevity	Janicki et al (1999)
Fragile-X	Mitral valve prolapse	Sreeram et al (1989)
	Musculoskeletal problems	Davids et al (1990)
	Early menopause	Conway et al (1998)
	Epilepsy	Ribacoba et al (1995)
Prader-Willi	Obesity related: Diabetes	Greenswag (1987)
	Heart conditions	Lamb and Johnson (1987)

Other health related needs specific to older people with a learning disability relate to the central nervous system damage associated with the person's initial disability, which can lead to increased vulnerability to conditions such as: epilepsy, cerebral palsy, and some forms of visual impairment (Evenhuis, 2001). There is of course the danger that syndrome-specific health conditions in older people with a learning disability may be perceived as inevitable and therefore little can be done about them. In a survey of 1373 older people with a learning disability Janicki et al (2002) found that over 50% were reported to be obese, yet staff and carers who responded did not see this as a health problem thus suggesting obesity may be considered as an accepted 'norm' for this population.

Janicki et al (2002) also found that sensory impairments (e.g. visual, hearing) were frequently found in the sample surveyed. Sensory impairments may be accepted as part of the normal ageing process but in this survey the age range was ≥ 40 -89 with 73% being under the age of 59 (i.e. a younger old age group). As Janicki et al indicate the high levels of sensory impairments in older people with a learning disability has been reported in previous research (Evenhuis 1997; Janicki and Davidson 1998).

Mental health problems and behavioural change

Research indicates that among the population of older people who have a learning disability there is a high incidence of mental health problems (Cooper, 1997; 1999). The prevalence of mental illness varies in people with a learning disability depending on where the population is drawn from. For example within a hospital for people with a learning disability it was found that 30% of people who were consider long-stay had a psychiatric disorder (Day, 1985). On the other hand Moss and Patel (1993) reported a prevalence figure of 11% with depression and anxiety being the main presenting

conditions. Percentage figures can also alter if dementia is included with other mental health problems (see section above on dementia). Overall, Parry (2002) states that depending on the survey and when old age is defined between 20-40% of older persons with a learning disability are liable to have a mental health problem.

The most common behavioural features reported in older people with a learning disability in the literature are dementia-related behavioral changes. Behavioural changes that have been reported include depressive features, wandering, psychotic symptoms and aggression (Donaldson, et al. 1997). It has been reported that challenging behaviours such as aggression are common in older people with dementia (Gardiner, 2002). However, misrepresentation of research results needs to be guarded against. Gardiner references Cooper and Prasher (1998) in support of the claim of increased aggression yet when this study was reviewed it was found that there was no significant increase in aggression in people with Down syndrome and dementia in comparison with others. While adaptive behaviour may decline in people with dementia, behaviours such as aggression are not always present. Two studies reviewed reported no significant increases in aggression in people with Down syndrome and dementia (Cooper and Prasher 1998; Cosgrove, et al. 1999).

Conclusions

Overall, what can be drawn from the literature in this section is that older people tend to have similar general health related problems to other older people. However, some do suffer the additional problems related to 'syndrome-specific' disorders and sensory defects associated with the aetiology of their learning disabilities. With regard to mental health a significant number of older people with a learning disability will have mental health problems, this being particularly so in the case of dementia in people with Down's syndrome.

Section 2: Social Factors, Inclusion/Exclusion & Policy Issues

The impact of the various health needs of older people with a learning disability can have far reaching affects for their family (carer), service commissioners and providers, and policy makers.

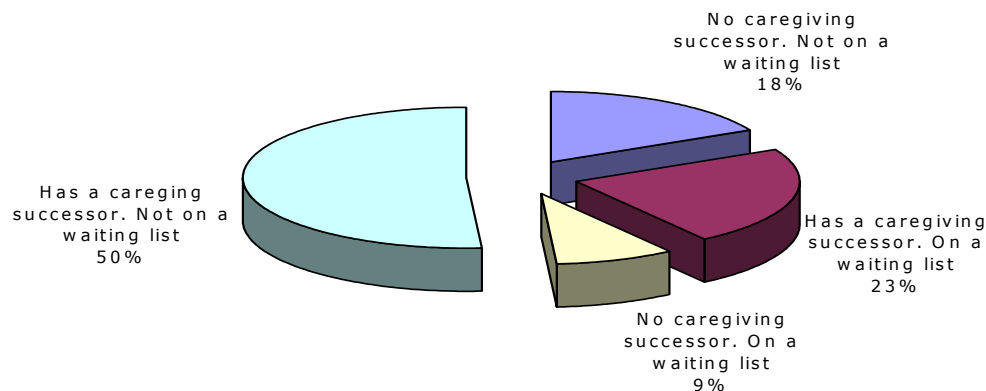
Family carers

As can be seen above age related health needs may arise in older people with a learning disability at a younger age than others (typically from ≥ 50 years). This being the case many of the parents of such individuals may be still alive and acting as their main carer. It is estimated that 30,000 family members in the UK over the age of 60 years are fulfilling caring roles for a relative with a learning disability at home, most (90%) being women (Lambe and Hogg 2003). Interestingly research has found that these older carers cope well and are reluctant to relinquish their caring roles (Krauss and Seltzer 1993). In this study of older carers it was unexpectedly found that the ageing carers coped very well (as well if not better than others) and explanations for not wishing to relinquish their caring role were suggested as being due to the following factors:

- Parents self-select to care for their son/daughter rather than having them placed in care
- After many years of caring parents adjust and accommodate to the caring role
- Parents build a long-term relationship with their son/daughter and do in fact gain and feel they have a purpose in life full-filling the caring role.

With regard to future planning in this study of older carers (387 families) Krauss and Seltzer found that only 9% anticipated an out of home placement for their son or daughter, most seemed to have planned well for the future.

Figure 1: Long-term plans of caring mothers of adults with learning disabilities



The Figure above cited in Krauss & Seltzer (1993, 54) illustrates this. These findings by Krauss and Seltzer (1993) demonstrating the resilience of older carers is somewhat

surprising in view of the many burdens on carers that have been identified (see Chapter 7 also).

Lambe and Hogg (1995) suggest the term that best describes the commitment of these carers is 'acceptance'. Older people with a learning disability who lose their primary carer, usually a parent, often lack having children of their own to help meet their needs and they do not always have a sibling to care for them (Ashman, et al. 1993). Many older people with a learning disability are left in a position where they have no other family member to care for them, Gibson, et al. (1992) use the term 'familyless elderly' to describe this group. Bigby (1997) states service providers usually take on the key role of primary carer for these older people when they lose their primary carer, even though some might have contact with significant others.

Policy issues and social exclusion

As can be seen in previous sections of this review older people with a learning disability have a number of specific health and social needs. These are in addition to the needs common to all older people and the growing recognition of 'ageism' in many societies (Slevin, 2003). However, among this population older people have been found to have additional high rates of untreated illness and under use of health services (Wilson and Haire 1990; Howells 1996; Patel, et al. 1993;).

In a study undertaken by Cooper (1997b) it is reported that older people with a learning disability received less:

- Day care
- Respite care
- Were less likely to have a social worker
- Received less input from most health services.

Many older people in general enjoy an active social life and some take on new careers. However, for the older person with a learning disability few have opportunities to take part in leisure pursuits (Rogers, et al. 1998). This is due to the health problems they face, perceptions of them as a lower social status group, exclusion rather than inclusive within their community and lack of support to access leisure activities (Browder and Cooper 1994). Not surprisingly, when access to leisure is so difficult for these people the chances of obtaining employment is even more difficult, in fact many have never had meaningful employment when they were younger (Ashman, et al. 1995).

If social inclusion is an underpinning philosophy of contemporary health and social care then questions need to be asked regarding the under-use of health and social services, leisure and occupational pursuits by older people with a learning disability. It seems that efforts to initiate inclusion have failed older people with a learning disability (Hogg, 1997). Even setting aside the issue of social inclusion it may be that older people are excluded from services within learning disabilities per se i.e. day care, respite and access to a social worker.

Robertson, et al. (1996) analysed community care plans from 1993/94 and found: 67% made no reference to older people with a learning disability; the remaining 33% made mention of older people only with respect to future policy; in 236 replies to a national survey they conducted in Britain 82% reported there was no policy in relation to older people with a learning disability.

Policies are now beginning to recognize the growing needs of older people, and their ageing carers. Valuing People (DoH, 2001) states that 25% of people with a learning disability only become known to statutory agencies in later life. This report also suggests there is a need to prioritize person-centred planning with people who live with older carers. However, in a survey for the Foundation for People with Learning Disabilities (FPLD, 2003) it is stated that the monitoring of needs of older family carers is ad hoc and poor. It seems that while policy directives aim for improvements in care such suggested improvements are slow to filter through to practice for this client group.

Conclusions

Family carers still bear the bulk of caring even when their relatives are elderly. Service commissioners and providers have been slow to develop policies and practices that address the needs of this population.

Section 3: Northern Ireland

Interest and research into the needs of older people with a learning disability is a relatively recent phenomenon. Within Northern Ireland there has been limited research that has focused directly on this client group. However, there are some studies which have identified need regarding older people with a learning disability.

Numbers

A recent prevalence study of people with a learning disability in Northern Ireland (McConkey, et al. 2003) identified the following:

- Out of 4,107 people with a learning disability living in ordinary homes 477 (12%) are aged over 60 years of age (see Appendix 8.1: Figure 1). Planning for the needs of older people with a learning disability should begin much earlier. Rice and Robb (2004) suggest it may need to begin at age 50 for some people due to various needs that have been identified in this review. If we applied this to McConkey's et al. figures then 1219 (30%) of these 4,107 people could be considered to fall within the older adult population.
- In Figure 2 (Appendix 8.1) McConkey et al (2003) identify the number of people with a learning disability living in residential or supported living. These figures show that of 1,358 people in supported/residential living; 375 were ≥ 60 years of age and if we consider the age of 50 (due to reasons above) as representing older age then ≥ 50 is 712 (52%) of these people who can be considered older adults with a learning disability.
- Figure 3 (Appendix 8.1) taken from McConkey et al (2003) identify the number of people with a learning disability who are long-stay in hospitals (defined as longer than one year). This shows there are 435 long-stay people in the hospitals in Northern Ireland. Of these people 53 (12%) are aged 65 years and over and one third of the hospital residents (285, 66%) are aged 45 years and older.
- Figure 4 (Appendix 8.1) presents figures from another study in Northern Ireland that investigated future housing needs in one board area (McConkey, 2003b). Figure 4 illustrates that 37% of carers for adults with a learning disability are over 65 years old. McConkey projects this to the other data presented and estimates that nearly 500 people live with a carer over 75 years of age and a further 1,000 persons with a carer aged 65 years.

Other studies have investigated the biographical details of hospital populations of people with a learning disability in Northern Ireland (McConkey, et al. 2002; Slevin, et al. 2002). The age population of this group of people are reflected in Figure 4 (Appendix 8.3) and have been discussed under McConkey's et al (2003) study above.

In one H&SSB area in Northern Ireland it was found that there was 217 families caring for people with severe learning disabilities where the mother was the sole carer, in contrast only 30 fathers held this role. In other words the mother was seven times more likely to be the sole carer than the father (McDonald and Mackay, 1997). This finding is supported in this review where previous research located also indicates that mothers are the main carers in most caring families.

McDonald and Mackay (1996) also investigated the prevalence of severe learning disability in Northern Ireland and found there to be differences in prevalence figures

with a west/south – north/east divide i.e. there were higher prevalence figures for severe learning disabilities in the SHSSB and WHSSB areas in Northern Ireland. There is a need for further investigation into this uneven prevalence spread and any such investigation should identify if this is also the case for older people with a learning disability.

Dementia

In a study in the EHSSB (Davies, et al. 2003) the authors undertook a needs assessment of people with a learning disability and dementia. They identified 43 people ; 42% had dementia, 9% were being assessed for the condition and 44% were considered by their key workers to be showing signs of dementia. 36 of these people were ≥ 51 year of age and 26 people had Down's syndrome (each person being aged < 65 years). In addition to identifying the prevalence of dementia Davies et al (2003) also identified current, and future need and present difficulties for these people across their various residences, these are summarised in Table 3.

Maybin (2002) in a survey of 44 older carers in one HSS trust found that deterioration in mobility of their ageing relative was the most common problem followed by the onset of epilepsy; reported by 45% and 33% of carers respectively. Most of their support came from social workers and GPs but rarely more than a visit once every six months to one year. Carers expressed little interest in knowing more about learning disability and dementia which may stem from an ignorance on their part about what this means. This were reluctance to attend formal training sessions preferring instead to have personal contacts or leaflets.

Conclusions

Although Northern Irish research is sparse in this area, the studies that have been undertaken tend to support the findings from elsewhere. As yet, specialised services for this client group with dementia are non-existent although the some of the elements of them have been described by a report prepared by the one HSS trust (Maybin 2002) . This theme will be develop further in the next section.

Table 3: Needs identified for a group of people with dementia in the EHSSB
(source Davis et al 2003)

Residence →	<i>Own Home</i>	<i>Residential Home</i>	<i>Nursing Home</i>
Suggested Need			
Current	Decreased mobility Confusion Sleep disturbance Supervision Vulnerable physical and mental state	Managing safe environment	Facilities not suitable Disorientation
Issues to be addressed now	Carer stress Carer not able to manage behaviour Carer's age Progressive incontinence House adaptation	Increasing physical & emotional care Increasing support Incontinence Higher ratio of staff	Increasing dependency on personal care and feeding
Anticipated	Respite for carer Constant care – residential/nursing Specialist unit Inability of carer to manage	Nursing care	Diagnosis Challenging behaviour

Section 4: Implications and Recommendations

The National Service Framework for Older People (DoH, 2001) relates to all people over 65 living in England. However, this age limit may exclude many people with a learning disability. Planning for the needs of these older people should begin much earlier, Rice and Robb (2004) suggest it may need to begin at age 50 for some people. This seems a logical argument and it is supported by the findings in this review where it is identified that older people with a learning disability are exposed to the same age-related health risks as others. But, additionally people with a learning disability typically develop age-related problems at a younger age than others; they are vulnerable to syndrome-specific, genetically induced and cognitively related difficulties. If 50 years of age is accepted as a defining age for old age monitoring of older people with a learning then the prevalence of older adults with this disability would increase significantly. This would be positive in a number of respects:

- The higher prevalence would lead to a stronger case for resource claims to meet the needs of this group
- Monitoring would allow early identification of potential problems and thus improved planning to meet this growing need
- Many potential crisis management situations could be avoided
- Service user and family education and preparation for growing old could be planned for earlier and therefore be more effective.

Practice guidelines

There has been a proliferation in recent years of the development of good practice guidelines across many areas of health and social care, these have been given more exigency by the clinical and social care governance agendas. Terms utilised include; clinical effectiveness, evidence-based practice, care pathways, clinical guidelines and best practice guidelines. These can be very useful to guide practice but before presenting some practice guidelines a word of caution is stated here. Practice guidelines are exactly what they state i.e. 'guidelines' and they should not be mistaken for 'rule based' directives. Practice guidelines can be very useful provided that this principle is kept in mind. The danger is that such guidelines lead to '*off the shelf*' practice with people being made to fit into the practice provided, rather than as it should be i.e. practice being individualized and based on individual assessment of need. Keeping this in mind there are some useful practice guidelines for service delivery to older people with a learning disability that can be integrated within individual person-centred plans.

Janicki, et al. (1995) (reproduced in Janicki, et al. 1996) in a workgroup for the AAMD have identified practice guidelines for the care of older people with a learning disability who have dementia, these include:

Identification

- Workers in adult services should be familiar with normal and pathological ageing processes
- Those who are at risk (e.g. people with Down syndrome) need to have periodic screening

- Staff need to be able to recognize early behavioural & clinical signs of dementia, which differ in this population e.g. memory loss (a usual first sign of dementia) may not present as such in a person with Down syndrome. More typical signs might be: new onset of seizures, personality change, loss of self care skills and apathy.
- A periodically used screening instrument should be used to establish behavioural baselines and thus facilitate future monitoring.
- Baseline monitoring should begin by at least age 40 in people with Down syndrome, and age 50 in others.

Conducting assessments and evaluations

- Information should be collected to confirm
- Continuing monitoring should take place
- Referral for diagnosis takes place
- Possible and probable diagnosis should be made based on criteria adapted from McKhann, et al. (1984) and included in the working guidelines of Janicki et al (1995).
- Detailed medical history informed by family member of clients key worker and involving the person his/her self as much as possible
- Physical and neurological examination and sensory testing
- Psychiatric assessment
- Appropriate diagnostic evaluations such as; EEG, MRI, CTT, X-rays, & pharmacological reviews to rule out overdose or side effects.
- Regular periodic assessment of activities of living (as appropriate for a person's degree of learning disability).
- Referral to specialist services such as gerontology

Instituting medical and care management

- Systematic treatment of all treatable medical conditions (should be as thorough as it would be for any member of the general population)
- Treatment of mental disorders such as depression (should be as thorough as it would be for any member of the general population)
- Frequent review of medications
- With progress of the dementia all functions will diminish and the person will require intensive support and nursing care
- Care management path involving documented & implemented strategies through all stages of the disease to include;
 1. Preservation of maximum function
 2. Interventions and support relevant for various stages of condition
 3. Multidisciplinary care planning

- Keeping family, friends and companions involved and informed as appropriate.

Education and training

- Training should be provided to care staff & family carers

Hogg and Lambe (1999) make the following recommendations regarding older carers:

- Services should support older family caregivers and engage in collaborative planning with them
- Service managers need to understand the nature and demands of caregiving
- Future planning should be sensitive to caregivers and older caregivers in particular
- Expert input will be required but parent support and networking with each other is valuable
- Cultural considerations of caregivers must be valued and respected.

Service Principles

Wilkenson and Janicki (2001) set internationally agreed principles and guidelines which they named the 'Edinburgh Principles' at a special meeting to define internationally applicable working practices for community supports for adults with a learning disability who have Alzheimer disease. These are summarised below:

Edinburgh Principles

- An operational policy that promotes the utmost quality of life
- Affirm that strengths, capabilities, skills and wishes should be the overriding consideration in any decision making
- Plan and provide supports and services that optimize remaining in the chosen home
- Ensure that generic, cooperative, and proactive strategic planning across relevant policy, provider & advocacy groups involves consideration of the current and future needs of the adult with a learning disability affected by dementia

(Note there are 7 main principles identified under the Edinburgh Principles 4 are listed here - excluded are guidelines that mirror those of Janicki et al above – refer to Wilkenson et al for the full listing)

Thorpe et al (2000) also state a number of principles that should be paramount in interventions for older people with a learning disability, these include:

- To develop living environments that are responsive to the mental health needs of the older person with a learning disability
- To promote mental health and minimize the affects of mental health problems
- To increase mental health services and supports in the community for this client group

- To collaborate with older people with a learning disability & their support systems in developing culturally sensitive, humane... interventions with an integrated [holistic] orientation
- To improve the quality of life in older people with a learning disability
- To develop a research agenda to provide evidence concerning each of these goals for all nations

(for a full discussion on these goals see Thorpe et al, 2000).

For guidelines on more practical aspects of meeting the needs of older people with dementia the reader should refer to McCarron (1999) who discusses:

- Making meal times a therapeutic event
- Using reality orientation (RO) in a sensitive therapeutic and caring way
- Validation techniques & ways to respond to confused people
- Leisure and entertainment to include:
 - Activities to achieve goals related to cognition, physical activity, social roles, psychological & spiritual well-being & self care
 - Activities that balance sensory stimulation with sensory calming
 - Activities that maximize functioning
- Encourage clients to set their own pace which can range from observation through to participation
- Finding alternative means of communication

(adapted from McCarron, 1999, 126-128).

Physical health

Most of the above principles and practice guidelines apply to dementia and focus on mental health, no such principles were located in this review with regard to physical health in older people with a learning disability. However, many of the good practice guidelines above apply equally to physical health. Broadly speaking it is recommended that these older people are offered the following:

- Regular physical assessments and health checks, at a minimum similar to others in society but due to their additional needs more monitoring might be required
- Treatments should not be with-held or delayed to anyone based on their age or the extent of their learning disability.
- Choice and informed consent should be a guiding principle.
- Access to the full range of primary, secondary & intermediary (step-down and step-up) care should be as a freely available as it is for others in society when required
- Collaborative shared care should take place (involving both client & family)
- Older people should not be forgotten with respect to health monitoring & promotion

- ❑ Care staff and professionals should be skilled to undertake health assessments at least to a level to allow recognition of health problems & the need for referral to an appropriate health professional

Education

There is a need emerging, which is evident from this review, to suggest consideration of joint working between the universities and service providers on a number of fronts that might include:

1. Ongoing advice of an in-service nature and short course provision of programmes that will prepare professionals to work with older people with a learning disability
2. Consideration of specialist course provision in gerontology practice in learning disabilities (to include dementia care)
3. To prepare front-line staff to be educators who are skilled at teaching carers
4. To ensure current learning disabilities education programmes include within curriculums appropriate content on working with older people who have a learning disability

Research

It is evident from this review that there is a need for a significant research programme within Northern Ireland on many aspects related to older people with a learning disability. Some of the research that has been cited in this review is extremely useful, especially McConkey's et al (2003) prevalence work that will make a significant contribution to future needs planning. However, there remains a paucity of research on the needs of older people with a learning disability in NI. If significant progress is to be made much more research needs to be commissioned in this area. A significant amount of the research that is presented in this review is national or international, and while undoubtedly some of this offers useful guidance to the local area, how much generalization can be made to NI is not always evident.

Conclusions

This review has synthesized the available evidence on the needs, care provision and identified problems of the older aged population of people with a learning disability. A number of assertions can be confidently made and among these are; that these older people are exposed to the same health and social challenges that face other older people in society, but that some of this client group are faced with additional needs related to their learning disability. Among these additional needs are syndrome-specific health problems, mental health needs that are at least similar to the general population, and in the case of dementia for some groups such as people with Down's syndrome significantly higher than the general population.

Some questions are forwarded for consideration and debate. The main argument to consider is that the normal convention of defining the beginning of old age as the age of retirement (65 years) has limited utility for people with a learning disability. The proposition for consideration is that learning disabilities services should consider lowering the age of their defined elderly population to 50 years for the purposes of health and social services planning.

The review highlights the current, and potential projected, needs of older caregivers. There is a need for identification and continued monitoring of this group of carers as

evidence suggests they many only come to the attention of services when care breaks down.

A number of 'good practice guidelines' that it is suggested will be useful to guide services here in the absence of guidelines based on local need are presented. The review concludes by detailed suggestions regarding education and research to meet future need.

Finally, the words of Turner, 1972 (cited in Slevin, 2003, 409) are presented as a poignant reminder of how we all might feel at some stage in old age, and how significant kindness, respect, interest and dignity can be to an old person (with or without a learning disability):

"If an old man sees that you are really interested in his personal life, you will see a wonderful transformation take place in him. His eyes that seemed dull will light up with a new fire; his face will come alive with unexpected emotion. He felt he had been thrown on the scrap-heap, and all at once he comes to life again, becomes a person once more. Just like the child, the old man needs to be spoken to and listened to in order to become a person, to become aware of himself, to live and grow. You will have brought about something that no social service can ever do of itself; you will have promoted him to the rank of person"

(Turner, 1972).

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Appendix 8.1:

The age distribution of people with a learning disability recorded on Trust information systems.

Figure 1: The number of people living in community settings (i.e. with family carers; own accommodation) in five-year age bands. (N=4107)

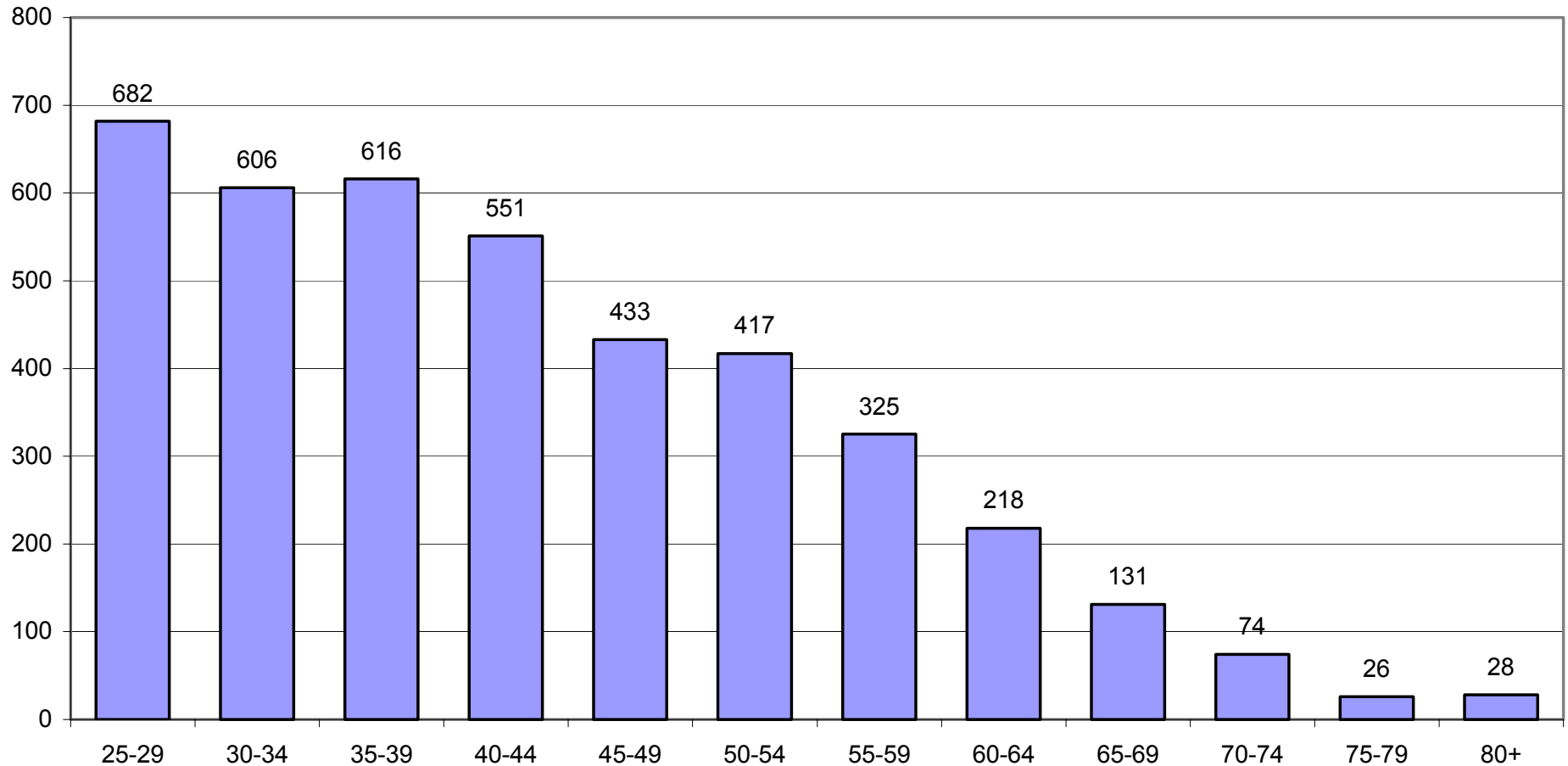


Figure 2: The number of people living in residential and supported living settings in five-year age bands (N=1358)

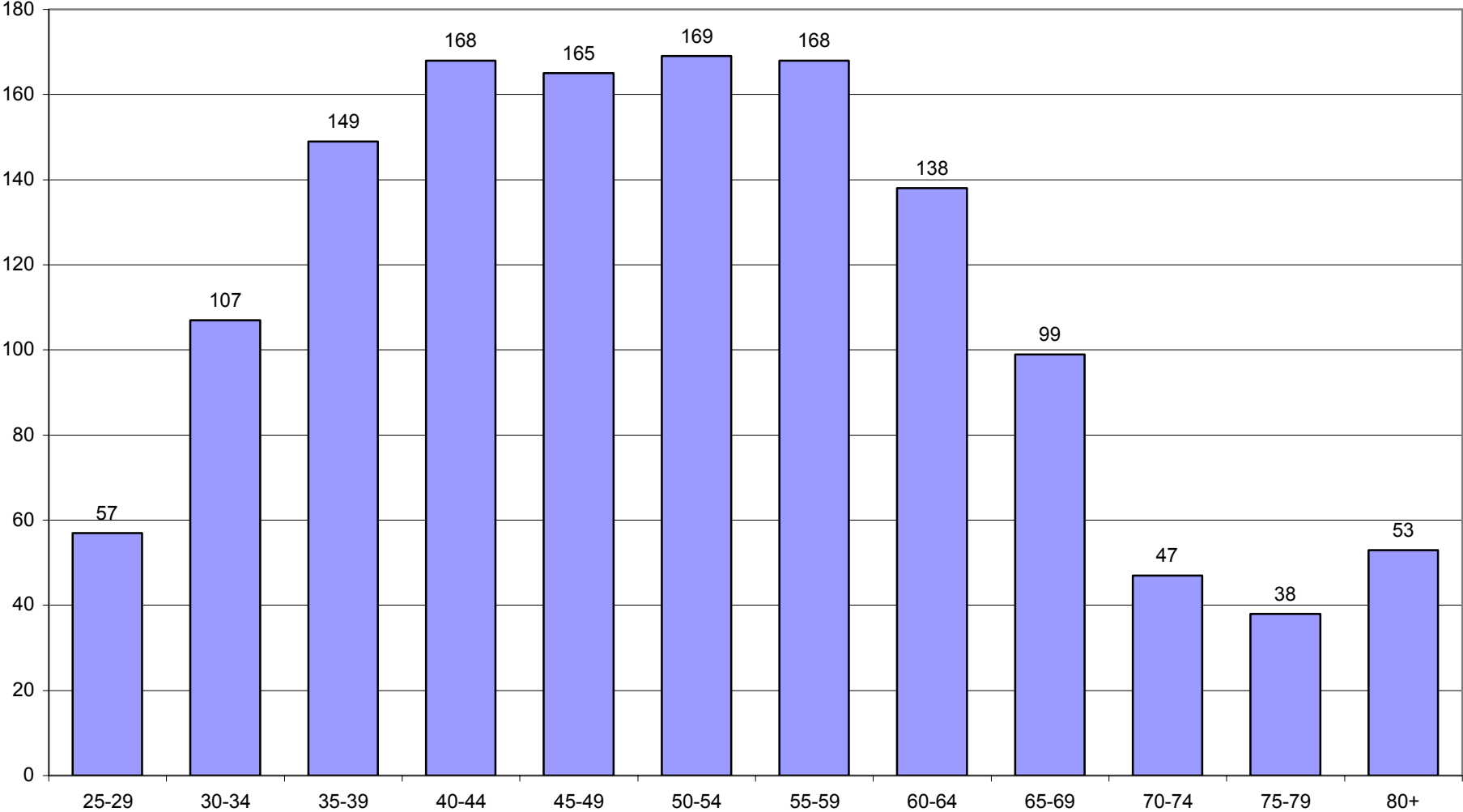
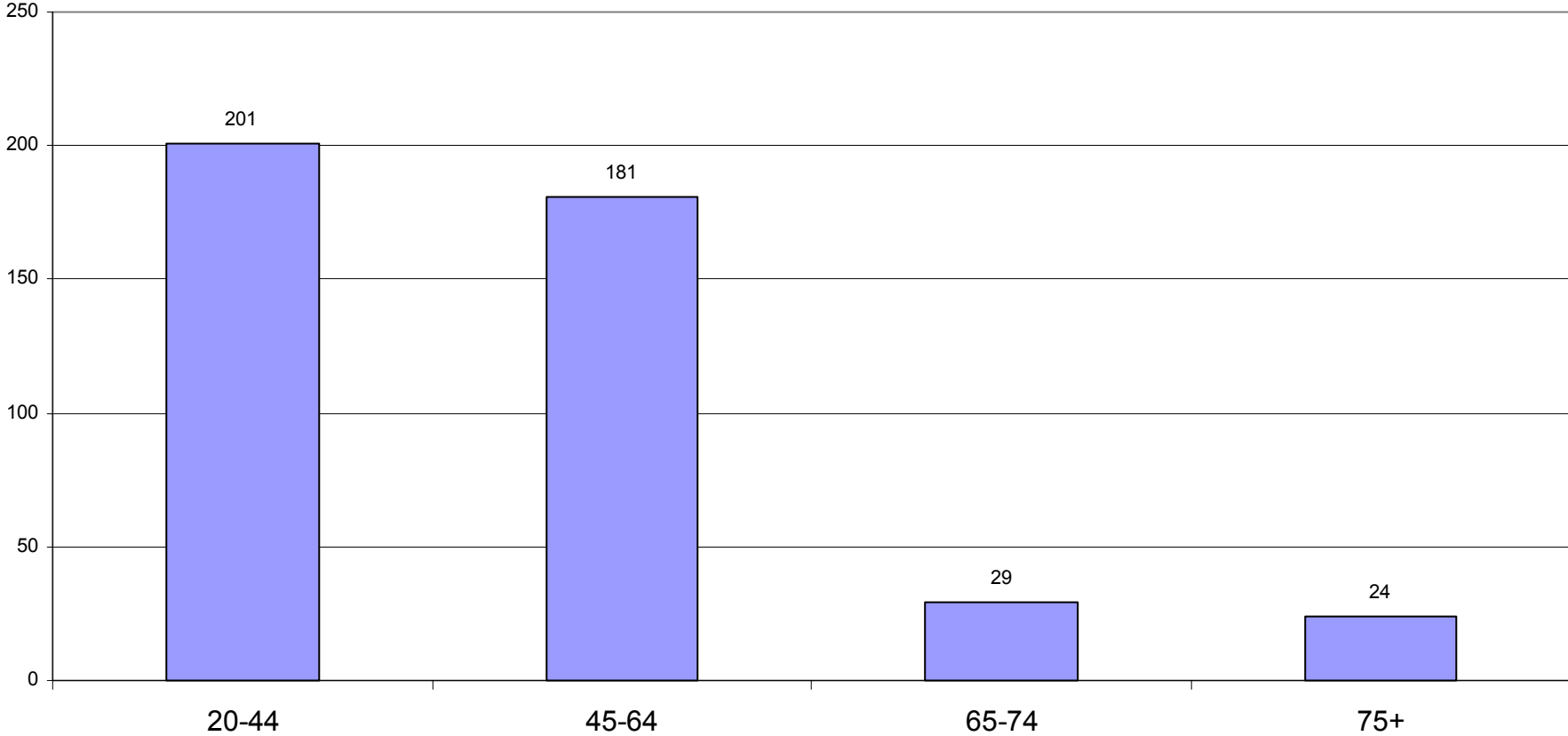
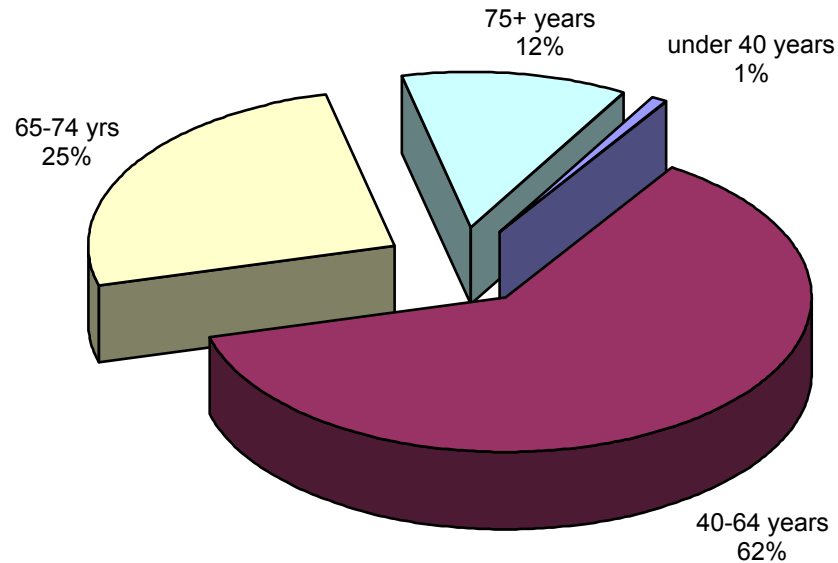


Figure 3: The number of in-patients in long-stay hospitals greater than 366 days (N=435)



Source: McConkey, R., Spollen, M., and Jamison, J. (2003) *Administrative Prevalence of Learning Disability in Northern Ireland*. Belfast: DHSS&PS.

Figure 4: The number and percentage of primary carers by age bands looking after people with learning disabilities aged 25 years and over in EHSSB area (N=436)



If these figures are projected to the population in Figure 1, this suggests that nearly 500 people live with a carer over 75 years of age and a further 1,000 persons with a carer aged 65 years (NB above the age at which paid carers retire!).

Source: McConkey, R. et al (2003) Future Housing and Support Needs of People with Learning Disability in EHSSB area. Belfast: NIHE/EHSSB

