

# **Ageing & Disability: A Discussion Paper**

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This Discussion Paper has been prepared as a contribution to a joint initiative on ageing and disability undertaken by the National Council on Ageing and Older People and the National Disability Authority. The basis for the work was provided by a literature review completed by Dr. Pauline Conroy and Ms. Ita Mangan. Further development of the paper, with the provision of additional material and editing, has been carried out by NDA staff.

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## **Introduction**

The 2002 Census in Ireland showed 136,000 people with disabilities over the age of 65. This represents 42% of the disabled population and more than one-third of people over 65. The population aged 65 and over in Ireland could increase from its present level of 436,000 to about 1 million in the next thirty years. The population aged eighty years and over is projected to increase three-fold in the same period, to over 300,000 (Punch 2005).

These simple facts give rise to questions about a possible 'common agenda' between people with disabilities and older people. Do people with disabilities and older people have similar health, housing, social, and transport service needs? Do they want similarly structured services? Do they prefer separate or integrated services? Do they experience similar types of social exclusion? Do they have similar concerns when seeking to claim their social, cultural and economic rights? A number of current trends make these questions relevant: projections of population ageing and a growing number of late-onset disabled people, the ageing of the disabled population, the higher proportion of women in paid work and concerns over the capacity of current support systems to cope with increased demand. Within the Irish health and social services people with disabilities and older people are constructed as two distinct client groups. Services are managed under two different National Care Group Managers within the Health Service Executive, and each group has a distinct budget. Similarly, differences in the social welfare entitlements of the two groups create anomalies in welfare provision. Given the boundaries set up by such administrative structures, questions arise as to how best to address the needs of people whose issues relate to both ageing and disability.

The National Disability Authority (NDA) is the statutory body charged with advising the Minister for Justice, Equality and Law Reform on disability policy. The NDA recognises that older people with disabilities form a significant proportion of the people on whose behalf the NDA works. The National Council on Ageing and Older People is an advisory agency to the Minister for Health and Children and others on all aspects of ageing and the welfare of older people. The NCAOP recognises that an age friendly society will also be a disability friendly society, given the numbers of older people who have a disability and the numbers of people with a disability who are old.

In 2004 the NCAOP and the NDA came together to begin to address these questions. Through the following discussion paper our two organisations hope to initiate constructive

dialogue about the ageing population with disabilities in order to develop, with Government and stakeholders, a positive national strategy for full participation and support of older people with disabilities, and to promote the implementation of such a strategy.

The following discussion provides an overview of developments on ageing and disability. Chapter One defines the key terms of 'disability', 'ageing' and 'dependency' within the context of current social policy debates. Chapter Two describes the key policy themes arising in current international policy and practice literature. Chapter Three considers disability data collection practice in Europe, Australia and Ireland and ageing data collection in Ireland. Chapter Four provides an overview of the situation in the Republic of Ireland for older people with disabilities. Chapter Five discusses ways that positive social policy for older people with disabilities can be implemented in Ireland.

Ultimately, two questions should guide our thinking: How can we create a society that enables the full participation of older people with disabilities, and how do we ensure that older people with disabilities receive the support they need in the manner they prefer.

## Chapter One: Defining Disability, Ageing and Dependency

### Disability

The National Disability Authority Act, 1999 defines “disability” to mean “a substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment.” Disability has traditionally been equated with physical, sensory and/or intellectual impairment. The classic ‘medical model’ locates disability as an individual problem, directly caused by disease, trauma or other health condition. Treatment is conceived of in terms of medical care (WHO 2002a, p.8). The ‘social model’ of disability originated in the disability movement in the U.K. and the U.S.A. The Union of Physically Impaired Against Segregation defined disability as

The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

(Union of Physically Impaired Against Segregation (UPIAS) 1976).

This social model distinguishes impairment, which is a condition of the body, from disability, which is a situation of social exclusion caused by the organisation of society. The model thus places the focus of change on social institutions and the environment, rather than on the individual. It also stresses the role of empowerment, participation and leadership of disabled people in effecting change. Though differences in interpretation of the social model exist, the influence of social factors on the experience of disablement has now been widely accepted, as evidenced in the WHO’s **International Classification of Functioning, Disability and Health** (WHO 2002a). A ‘post-social’ model of disability that incorporates aspects of both the social model and the medical model will form the basis for the upcoming post-censal National Disability Survey.

### Ageing and the Life Course

Ageing is often equated with chronological age. Concern about population ageing, in chronological terms, has resulted in widespread debate on an impending ‘demographic timebomb’ and increased ‘dependency ratios’. Connell and Pringle (2004) define

'dependency ratio' as "the ratio of those in the population considered to be dependent (below 15 years and above 65 years), to those considered to be of working age (15-64 years)" (p.82). Leeson (2004) identifies 5,500 economic evaluations of the costs of an ageing population, but argues that mortality and health care expenditure is increasingly linked not to chronological age, but to life style, behaviour and diet. The limitations of chronological age as a basis for social planning have been identified in international policy, where chronological age has been described as a "crude tool" for identifying needs of particular population groups (United Nations Population Fund 1998). Characterisations of the ageing population in terms of "dependency ratios" project negative images of ageing as dependency and do little to define the diverse needs of older people (See NCAOP 2005a, pp.31-32). In addition, such characterisations serve to hide the valuable contribution older people make to society. For example, grandparents provide a substantial amount of unpaid care to the 54,000 families in Ireland whose parents both work, while in 2002 over 16,000 people aged over 65 identified themselves as primary carers (Good & Fitzgerald 2005, p.25). Though statistics about demographic change have value in highlighting the changing formation of our population, it is important to distinguish chronological age as a statistical fact from the process of ageing as a complex phenomenon with physical, psychological, cultural and social aspects.

Ageing has traditionally been associated with physical and mental decline. It is conceptualised in terms of loss of faculties. Kennedy & Minkler (1998) discuss the origins of this linkage in relation to industrialisation. In the late 1800's, political, economic and other social forces resulted in a gradual devaluation and medicalisation of old age (p. 769). Critical gerontology theorists argue that old age is increasingly being conceptualised as a medical problem (Robertson 1997, p. 427). Hannah McGee claims, however, that we need to distinguish the medical conditions of older people from the prejudice and discrimination which operates through our economy and society (McGee 2005, p.30).

More recently, ageing has been conceptualised in terms of a life cycle, or life course. As Bigby states, "ageing is a process, not an event" (2004, p.19). According to a life course approach, generational categories of ageing shift over time, are embedded within culture and are shaped by structural processes of social change (Priestley 2003, p.21). The life course approach focuses on how the organisation of society creates generational categories. For example, Priestley and others have argued that both disability and ageing are produced in

society through labour market exclusion (*Ibid.*, pp. 143, 146). Both people with disabilities and older people are often excluded from work. For older people, their identity as a distinct category has been underscored by the development of pension policies that require retirement at a fixed age. Similarly, disability theorists have argued that the category of 'disabled people' has arisen out of the exclusion of people with disabilities from the adult labour market as a result of industrialisation (Oliver 1993, p.253).

It is suggested that life course categories are more useful in analysing ageing and disability than chronological categories. Bigby points out that the definition of "older person" differs between disabled and older people's services; services for people with disabilities may define persons aged 50 and over as old, whereas services for older people are often designed for people over the age of 75 (Bigby 2004, p.245). A life course approach enables analysis of the diversity of ageing experiences by examining the different trajectories of transition from adulthood to old age for different social groups.

Recent social policy statements have sought to re-define ageing in a positive way. The World Health Organisation (WHO) defines 'active ageing' as "the process of optimising opportunities for health, participation and security in order to embrace quality of life as people age" (WHO 2005). The term 'active ageing' emphasises the continuing participation of older people in the social, economic, cultural, spiritual and civic affairs of society (WHO 2002b, p.12). The WHO's policy document **Active Ageing: A Policy Framework** (2002) supports a life course approach to ageing, and sets out the key determinants of active ageing which are social, environmental, behavioural, economic, personal and health/social service related.

'Successful ageing' is a concept developed in part through the MacArthur Foundation study on ageing. It is also sometimes referred to as 'positive' ageing, or 'productive ageing'. The **Successful Aging** report defines successful ageing in terms of the ability to maintain three key behaviours or characteristics: low risk of disease and disability, high mental and physical function and active engagement with life (Rowe & Kahn 1998, p. 53). While social participation is connected with one of these factors, it can be seen that this definition is heavily reliant on physical and mental health. Kennedy & Minkler have criticised the association of successful ageing with physical health, arguing that such a linkage "not only reinforces the valuing of people primarily in economic terms, but further marginalizes groups such as caregivers and the elderly, who are already excluded from the labor force" (Kennedy

& Minkler 1998, p. 772). By seeking to affirm the value of older people through a commitment to healthy ageing, policymakers may undermine the value of people with disabilities. In so doing, some ageing activists may have “traded earlier, limited views of ageing for an even more limited view of what it means to be old and disabled” (*Ibid.*, p.769). The NCAOP has argued that older people should not be constrained by a single version of ageing, either the ‘deficit’ model, which sees old age as an illness without cure, or the ‘heroic’ model, which suggests that to age successfully you must maintain the appearance, capacities and perspectives of youth and middle age (NCAOP 2005a, p.31). When considering ageing policy it is important to ensure that frameworks promote the inclusion of all older people, whether or not they have impairments.

### **Dependency**

The Australian Institute of Health and Welfare (2000) defined dependency as “a state in which an individual is reliant on others for assistance in meeting recognised needs”. Such a definition of dependency presupposes that disablement is located in the individual and that disablement necessarily leads to dependency. Morris (1999) describes how dependency, like disability, has been associated with being helpless, powerless and vulnerable. This view of dependency focuses on loss of control and leads to a biologically-based association between dependency and impairment. From this perspective, dependency is often viewed as a necessary consequence of chronological age. The focus on dependency ratios within international debates concerning the ageing population presumes that people of a certain chronological age will require substantial support. Discussion then focuses on how to increase the numbers of younger people in work to provide enough funding for long-term care (see for example, the European Commission’s Green Paper “Confronting demographic change: a new solidarity between the generations”, 2005). Robertson (1997) uses the phrase “apocalyptic demography” to describe “the prevailing belief ... that an increasing ageing population inevitably means increasing demands on the resources of society, including health care resources, in the face of competing interests and diminishing, or at best finite, resources” (p. 426). This view has been challenged by recent evidence which shows a decline in the proportion of older adults who report certain activity limitations (Singer & Manton 1998). So too, Manton, et al. 1997 reported statistically significant declines in chronic disability prevalence rates in the elderly United States population between 1982 and 1989. This new evidence has led to suggestions that there may be a compression of

morbidity, rather than a lengthened duration of disability amongst the older population. It highlights the diversity in the dependent population and the need for more complex analyses of dependency.

Rather than dependency being equated with the need for assistance, it should be understood as the consequence of a failure to provide the means for effectively negotiating assistance. Bould, et al.'s definition of dependency is helpful in this regard, as it distinguishes dependency from loss of self-determination. Dependency is "a loss of self-determination that results from requiring the help of others but being unable to negotiate the terms of the help received" (Bould, et al. 1989).

### **Dependence, Independence and Interdependence**

The Independent Living Movement has sought to break the association between dependence and being able to do things for oneself. They have challenged the idea that to rely on others for physical help inevitably means a loss of choice and control. Morris (1999) argues that this is due to socially constructed unequal power relationships within care. Giving individual people with disabilities purchasing power over care through direct payment schemes fundamentally changes care relationships from those of dependence to independence (pp. 11-13).

Recently Good & Fitzgerald (2005) drew a distinction between 'necessary dependency' that is an integral part of being human, and 'social dependency' that is a product of the interaction between the individual's life situation and the structures and systems within which that individual lives. This distinction has parallels with the social model of disability as described above. Like the social model, a social conceptualisation of dependency puts the focus on society's role in producing dependency. The suggestion is that dependency can be reduced through changes in attitudes and in the physical environment. Social dependency focuses on whether society has created structures and supports that facilitate and maximise independence.

Some writers have suggested that a focus on dependence and independence unnecessarily portrays the issue of care in terms of two extremes. According to this view, modern society is rooted in a 'radical individualism' bestowed upon us from Enlightenment thinkers (Robertson 1997, p. 435). This individual actor regards interpersonal interactions in terms of the social contract and envisages him-self as a self-reliant, self-sufficient being (p. 435).

But Formosa (1997) describes the reality for older people as an ‘interdependent lifestyle’ which involves reciprocal care between friends, neighbours and families. Robertson (1997) argues in favour of a ‘moral economy of interdependence’. She suggests that “the fact that we live in community means that we are ‘ipso facto’ interdependent”, and that this is evidenced by a modern welfare state which institutionalises reciprocity (p. 437). She argues that what is needed is a recognition that we are all interdependent. The moral economy of interdependence would allow for moral discussion on the issue of need (p. 438). It would also require that we decommodify reciprocity, acknowledging that much of what is undertaken in caring cannot be measured (p.439). This suggests that only by taking into consideration our universal interdependence can the pervasive informal labour of care be adequately understood.

### **Summary of Key Points:**

- Both ageing and disability have traditionally been associated with physical, sensory, intellectual and/or mental impairment. Policy on the treatment of both has historically focussed on institutional arrangements of medical and social care.
- For both older people and people with disabilities, theorists and policy-makers increasingly recognise the social factors that influence their situation. In the ageing sector, such discussions focus on a life course conceptualisation of ageing, while within the disability sector this is framed in terms of a social model of disability.
- The issue of dependency is one that impacts on older and disabled people, both of whom have been conceptualised in public policy as especially reliant upon others. Both groups can benefit from a conceptual distinction between necessary dependency and social dependency that can shift social policy towards facilitating greater independence.
- Recognition of the universality of interdependence may provide a way to underpin greater connectedness and reciprocity within communities for all people.

## Chapter Two: Key Themes in International Policy & Practice

An international review of literature on ageing and disability has generated the following key themes. A number of these represent common or overlapping issues for the two groups. Certain issues are discussed that arise differently for people with early-onset disabilities and people who acquire disabilities in old age. In general, it is evident that joint working between the ageing and disability sectors is relatively new. There are examples of good practice in a number of countries, but there is as yet little evidence of a thoroughly integrated approach to policy towards older people with disabilities. It is also evident that older people with disabilities are treated by-and-large as a homogenous group, with little recognition of diversity issues. The issue of gender is neglected. In the policy literature reviewed below, little or no mention was made of the fact that the majority of older people with disabilities are women. Also missing from the policy literature are discussions of the issues for older people with disabilities who come from other socially excluded groups. Walsh & LeRoy's qualitative research on older women with intellectual disabilities provides evidence of the differing place of people with disabilities and of older people within different cultural contexts (2005). However, their work is unusual, and in general policy literature on ageing and disability does not articulate the issues for people from different ethnic groups living within a country. Neither are the issues for older gay, lesbian and bi-sexual people addressed in the literature reviewed.

### Rights

Comparison of the **UN Principles for Older Persons** (1999) with the **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (1992) shows a number of overlapping concerns. The **UN Standard Rules** outline key preconditions for equal participation of people with disabilities in society. The **Rules** assert that persons with disabilities have the right to remain within their local communities (UN 1992, para. 26). Similarly, the **UN Principles** assert that older persons should remain integrated in society (UN 1999, para. 7). Both documents call for actions to support independence and autonomy (UN 1992, Rule 3, UN 1999, para. 12). Both documents call for services to assist people to reach their optimum level of function (UN 1992, Rule 3; UN 1999, para. 11). Both documents assert the right of people to accessible environments (UN 1992, Rule 5; UN 1999, paras. 5 & 6). Both documents support the fundamental right of all people to participate in society.

Very little literature seems to address the relationship between rights claims of people with disabilities and older people. Priestley & Rabiee (2002) have conducted research on this area in the U.K. Their research examined older people's views on disability issues through a survey of older people's organisations. Issues of common concern included mobility and transport, accessible housing and independent living. For example, groups representing older people have advanced similar claims to people with disabilities about the right to live in the community (p. 603). A particular instance of the two movements working together occurred in the winter of 2000, when a campaign launched by Disability Now for the extension of cold weather payments to disabled people over 65 was supported by older people's groups (p. 607). Priestley contends that very little attention has been paid to the political significance of the common claims of older people and people with disabilities (Priestley 2002, p.362). He describes how self-advocacy among both older people and disabled people is increasingly common. Concluding that there are good reasons for collaborative working on rights issues, he also acknowledges that there are distinct orientations within each group which may create barriers. Priestley argues that the promotion of 'active ageing' by older people's organisations in the UK signifies a desire to distance themselves from images of physical frailty, and may discourage support of disability issues (*Ibid.*, p.368). On the other hand, the focus in disability campaigns on participation in work offers little to retired older people.

### **Independent Living (Consumer-Direction)**

The desire to be independent has been expressed by both older people and people with disabilities. In Priestley & Rabiee's study of older people's organisations in the UK, independent living was rated as "very important" by more organisations than any other issue (2002). In Ireland, the NCAOP's survey research shows that older people would prefer to remain in their own homes (2005a). So too, the American Association of Retired Person's survey of people aged 50-64 living with disability says that their number one fear is loss of independence (AARP 2003). Disabled people have advocated the independence of people with disabilities from exploitative relations of care since the 1970's. The Independent Living Movement has defined Independent Living in terms of the right of all persons to participate and reside in the community and control and make decisions over their own lives (The Canadian Association of Independent Living Centres 2003). As discussed above, the

Independent Living Movement has highlighted the distinction between ability and dependency (Morris 1999).

The international literature shows the increasing influence of independent-living concepts on ageing policy. This is most evident in the USA, where the Independent Living Movement originated in the 1970's. In this setting, the terminology 'consumer-directed services' is prevalent. The use of the term 'consumer' is contested in Ireland; it may misrepresent the Irish context of formal care that is predominantly within citizen-supported statutory services. However, discussion in the American literature uses the term 'consumer' to refer to service users. Simon-Rusinowitz (1999) claims the ageing community in the USA increasingly accepts the need for consumer-directed services (p. 2). In one survey, results projected that between one-third and one-half of older consumers would be interested in a cash benefit consumer-directed option (Ibid., p. 6). Similarly, Simon-Rusinowitz's survey of policy experts in the field identified a large upsurge in interest by researchers and policymakers in the ageing sector regarding consumer-direction. They also cited numerous examples of joint implementation initiatives between ageing and disability services (Ibid., p. 7). Policy experts identified three key factors in increased implementation of consumer-directed services for older people:

- 1) Hopes that consumer-direction would result in lower-cost services;
- 2) Leadership from the Clinton Administration's Health Care Reform Task Force that resulted in both dissemination of information about consumer-directed services and funding for pilot projects; and
- 3) Changing demographics, i.e. the ageing population, and a growing emphasis on consumerism and empowerment generally (Ibid., pp. 8-10).

The American Association of Retired Persons published a report in 2003 on independent living and disability. Based on a survey of people over 50 with disabilities, it finds that older people with disabilities want more direct control over their long-term support services (p. 8). It describes a number of innovative programs to enhance independent living. 'Cash and Counseling: Demonstration and Evaluation' is a study of consumer-directed personal assistance services for older people and younger people with disabilities. Using a cash benefit, consumers choose who provides personal assistance services. The benefit can also be used to buy other services to facilitate independence such as transportation, home

modifications, and assistive devices. Counselling and bookkeeping support is offered to assist consumers in decision-making and management of the services (University of Maryland 2002). In a project on assistive technology in Massachusetts, case managers identified suitable clients, helped clients to order equipment and trained them in using it (Gottlieb & Caro 2001). It is useful to note that Simon-Rusinowitz identifies a number of problems with the implementation of consumer-directed programs in the USA. There is still limited knowledge about how to implement consumer-direction (Simon-Rusinowitz 1999, p.11). Policy experts identify fraud and abuse, quality assurance, consumer capacity to manage services and resistance by provider agencies as issues of concern (Simon-Rusinowitz et al. 1999).

The AARP Report also describes recent developments in Europe. Germany had the largest user-directed service program in Europe in 2003. There the Government introduced a social insurance program for long-term care that includes a cash benefit option. Uniquely, participants are allowed to use this cash benefit to pay informal caregivers as well as formal services. In the Netherlands, beneficiaries receive a budget that must be used to buy services. France provides a cash allowance, but most of it must be used to pay for external assistance. Austria, France, Germany and the Netherlands all allow beneficiaries to either hire or pay family members to provide assistance, and this is allowed in certain USA programmes as well (AARP 2003, pp. 171-172. See also Wiener, et al. 2003).

Ireland has an active independent living movement, with 27 Centres for Independent Living. The Centres support people with disabilities to achieve independent living, choice and control over their lives. First established in Ireland in 1992, the Centres may offer a valuable resource of experience to the ageing sector.

### **An Age Friendly Society and A Disability Friendly Society**

The NCAOP has recently called for an 'Age Friendly Society'. Their Position Statement states that an 'Age Friendly Society' seeks to optimise the opportunities for health, participation and security of citizens as they age. Such a society will enable the achievement of productive, positive and successful ageing, while acknowledging those who have other aspirations. An 'Age Friendly Society' makes older people the key stakeholders in determining the supports they need to enhance their potential. It supports positive images

of ageing (NCAOP (2005a), pp.26-27). An 'Age Friendly Society' "will also be a disability friendly society," and "will do all in its power to reduce the social and physical isolation of both older people and disabled people of all ages." (Ibid., p.39).

### **'Livable Communities'**

Recent policy in the USA and the Netherlands demonstrates thinking that integrates the needs of older people and of people with disabilities around the development of a society for all ages. Policy literature in the USA by both older people and disability organisations has focussed on the idea of 'livable communities'. The National Council on Disability published a report on livable communities that emphasised the common needs of people with impairments of all ages, and that built on earlier work on "elder-friendliness" (NCOD 2004). Similarly, the American Association of Retired Person's policy report for 2005 focuses on 'livable communities' (AARP 2005). In it, a 'livable community' is defined as

"one that has affordable and appropriate housing, supportive community features and services, and adequate mobility options, which together facilitate personal independence and the engagement of residents in civic and social life" (AARP 2005, p. 16).

The report recognises that homes, neighbourhoods and transport affect the ability of people to engage in community life (Ibid., p. 20).

By emphasising the connection between the physical organisation of a community and the ability to participate in it, such a statement highlights the link between an 'Age Friendly Society' and a 'Disability Friendly Society'. Many of the characteristics required for 'livable communities', such as supporting home adaptation and universal design in home-building, developing accessible community public transport, and providing access to health and social services are of benefit to both older and disabled people. The adoption of a life course perspective, by recognising the universality and continuous nature of the ageing process, leads to initiatives such as 'livable communities', as we recognise that ageing and impairment are common experiences of people living within our local communities.

Such an approach is also evident in recent developments reported from the Netherlands. The Dutch Government is promoting the efforts of senior citizens to continue to live in their own homes, and promoting arrangements for informal and community-based care (Bakker, 2005, p.8). Effort has gone into physical adaptation of existing homes, and into integrated

community designs for housing and care. The focus in the Netherlands is on building assisted-living complexes. These consist of modern apartments where tenants do their own house-keeping independently as much as they are able. Complexes include a day centre for those needing structured support, as well as physical therapy space. A key difference between this and older community residences is that the services in the complex are intended for use by the neighbourhood inhabitants. Older people with dementia are accommodated in small-scale housing groups in ordinary neighbourhoods. Both of these types of housing are part of what is called a 'home-care zone' or 'home-service zone'. These zones cover about 10,000 inhabitants, with a central multifunctional building containing core services and high-support accommodation, and accommodation for people with varying levels of need radiating outwards from this facility (Bakker 2005, p.17).

### **'Ageing in Place'**

The concept of 'ageing in place' is relevant for both older people and people with disabilities when talking about 'livable communities'. Ageing in place refers to the ability of people to remain in their homes and communities as they develop impairments. It means deferring transition to institutional care for as long as possible. It also means enabling the social integration of people who develop impairments (see UN Human Settlements Programme 2002). Responding to the preferences of people who develop impairments means providing an accessible environment and supports to allow them to continue to live in their communities. It is also important to recognise that 'ageing in place' for people with early and mid-onset disabilities may mean remaining in disability-specific residential and community services. For people who have developed long-term relationships within disability services, the transfer to older people's services may not reflect their needs or desires. For some people, 'ageing in place' means providing adequate ageing supports and care within disability services. In all cases, the decision to 'age in place' should be made by the person with a disability.

### **Gender, Ageing & Disability**

The 2002 census statistics show that 62% of people with disabilities over the age of 65 are women. Yet, as stated above, there is very little discussion in the literature on the particular issues for women ageing with a disability. Matthew Janicki has recently stated that "much of the extant ageing research and literature has ignored the needs of women with disabilities and has not offered insights into their particular challenges and the means many have used to overcome their problems" (Janicki 2004). **Women with Disabilities Aging Well: A**

**Global View** reports on qualitative research with women with intellectual disability across 18 countries. This research begins to describe the experience of ageing for women with intellectual disabilities, and to distinguish the differences in this experience within various cultures (Walsh & LeRoy 2004). It is difficult to extrapolate particular policy implications for Ireland from this report, given that its conclusions are based on information from both developed and developing countries around the world. One valuable insight is that older women with early-onset disabilities do not live out the same life trajectories as women who develop disabilities in later life (*Ibid.*, p.7). Such women may be socially excluded from an early age and may be less likely to have children who will care for them in old age. It is also important to consider gender when reviewing statistics on morbidity. Statistics show that women live longer with impairment, and have fewer morbidity-free years than men (*Ibid.*, p.12). It should also be acknowledged that older men with disabilities may encounter distinct difficulties. The social isolation experienced by older men with disabilities may be qualitatively and quantitatively different from that of women, and there may be some differences in the supports and services needed.

### **Mental Health and Ageing**

Policy in mental health and ageing is relatively under-developed. Mental health problems are common amongst older people. In the UK, estimates are that 40% of GP attendees, 50% of general hospital patients, and 60% of care home residents have mental health problems (DH 2005, p.1). In the US, older men experience the highest rate of suicide compared with all other age groups (President's New Freedom Commission 2003).

The UK's **National Service Framework for Older People** contains guidance on national standards for service delivery for older people with mental illness (DH 2005, Appendix 2). Their Department of Health has recently launched a new joint initiative between the mental health and older people's service divisions. This established a programme board for older adult mental health services with representation from both older people's and mental health policy (DH 2005, p.1). A service development guide was planned for Autumn 2005.

In the United States, the President's New Freedom Commission report on mental health highlights gaps in services for older people. It identifies shortages in workforce capacity in the areas of geriatrics and mental health and ageing. It confirms the high prevalence of mental disorder amongst older people, and a lack of preparedness on the part of services to cope with this growing population. The report emphasises that a greater degree of stigma

against mental illness exists within the older population, and this deters older people from seeking treatment (President's New Freedom Commission 2003). Guidance on mental health and ageing is also found in the Administration on Aging's report **Older Adults and Mental Health: Issues and Opportunities** (2001), which contains in-depth discussion of the challenges and strategies for providing effective mental health services to older people. One policy development in the USA has been a joint initiative by the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Council on the Aging, Inc. (NCOA) to highlight good practice. Their publication on partnerships between substance abuse, mental health and ageing services aims to promote linkages between these sectors by giving examples of successful programmes (DHHS undated).

There is some evidence of discrimination against older people in the treatment of mental health problems. Lagana & Shanks (2002) found that many mental health professionals hold negative attitudes towards older people. Fischer, et al. (2003) examined treatment of older patients for depression in Primary Care. They found that providers were only 6% as likely to ask old-old depressed patients about suicide risk, about one-fourth as likely to refer them to a mental health therapist, about one-fifth as likely to ask if they felt depressed, and one-twentieth as likely to ask about a problem with alcohol as they were with young-adult depressed patients. They conclude that there is a possible pattern of under-attention to depression in the oldest population.

It is also important to acknowledge the long-term effects on mental health of the social exclusion experienced by people with early and mid-onset disabilities. The impact on mental health of social exclusion is well-documented. People with long-term disabilities are at higher risk of mental health difficulties in so far as they are socially excluded.

### **Summary of Key Points:**

- The desire to remain independent has been expressed by both older people and people with disabilities.
- The Independent Living Movement is increasingly influencing ageing policy in the USA and Europe. This influence has led to the provision of consumer-directed and personal assistance services to people with disabilities and older people.
- Older people and people with disabilities have established common rights claims within the United Nations arena.
- Research in the U.K. indicates scope for joint working on political issues, in particular mobility and transport, accessible housing and independent living.
- The connection between the physical organisation of a community and the ability to participate in it highlights the link between an 'Age Friendly Society' and a 'Disability Friendly Society'. This is being operationalised internationally through 'livable communities' and 'home-care zones'.
- There is a lack of discussion in policy literature about particular issues for older disabled women and men, for older people with disabilities from diverse ethnic groups, and from different sexual orientations.
- Women represent 62% of the population of older people with disabilities, and live longer with disabilities than do men.
- Policy in mental health and ageing is under-developed. Existing literature suggests a lack of service provision, poor co-ordination, poor access to services and a high level of stigma around mental health issues amongst older people.

## **Chapter Three: Disability Prevalence Data**

### **Disability Data in Ireland**

It is clear that policy makers and service providers need reliable indicators of service and other needs. The 1996 Commission on the Status of People with Disabilities identified that this was an area that needed to be addressed in the Irish context. Since 2001, the NDA has been working to ensure implementation of the Commission's recommendations. Significant progress has been made, perhaps most importantly with the approval by Government of the first Irish National Disability Survey which will be carried out in September 2006 by the Central Statistics Office as a post-censal exercise. The questionnaire to be used in this survey is currently being finalised based on the pilot questionnaire developed by the NDA in 2003. The questionnaire will contain sections on impairments, on aids and supports both available and needed and on policy areas such as education, employment, training, transport and the built environment. The National Disability Survey will cover all age groups within the population, including those over the age of 65. It will also cover both people living in private residences and those in institutions. The intention is that this survey will provide for the first time the baseline data required by policymakers and service providers. It is hoped that such surveys will be carried out at regular intervals, possibly every 10 years, as is the case in other countries. This will enable the Irish state to evaluate its progress towards equality for people with disabilities.

A further initiative in which the NDA is involved addresses the central challenge of disability data collection, and that is ensuring an agreed definition to underpin all data collection exercises within the EU. This project, entitled Measuring Health and Disability in Europe, is examining the World Health Organisation's International Classification of Disability Functioning and Health (ICF) as a framework for disability data collection across the European Union. The MHADIE Project began in January 2005 and will continue until the end of 2007.

The Health Information and Quality Authority (HIQA), as a newly-formed agency reporting to the Minister for Health & Children, will also have a key role to play in the development of better health information about older people and people with disabilities. The responsibilities of HIQA will include developing health information, promoting quality assurance and overseeing health technology assessment. The Minister for Health and

Children has forwarded the National Standards for Disability Services to HIQA for consideration.

Pending the outcome of these initiatives, other developments since 2001 have given a partial picture of the situation for people with disabilities in Ireland. These include the 2002 Census, the Quarterly National Household Surveys, and the national intellectual and physical and sensory disability databases.

The 2002 Census of Population included two direct questions on disability for the first time. When combined with the array of socio-demographic information collected through the Census, it was possible to examine extensive information on the situation of disabled people in the State. It provides quite extensive information on people with disabilities, including a detailed breakdown by age and type of disability. The information is based on self-assessment, and does not indicate the needs arising from the particular disability. Nevertheless, as a positive development it went some way to correcting the 'silence of official statistics' in Ireland on people with disabilities which had been noted by the Commission on the Status of People with Disabilities in 1996. The Quarterly National Household Survey carried out in the second quarter of the same year included a special module on disability. It focussed on whether people had any long-standing health problem or disability, the nature of that problem/disability, and the labour force status of those affected (Nolan, et al. 2003).

Statistics are also available from service providers through a number of national databases overseen by the Health Research Board (HRB). The National Intellectual Disability Database (NIDD) collects information on the users of services for people with intellectual disability. It currently has over 25,000 registrations. The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need. Data is reported regionally, including information on residential circumstances by age group and degree of disability.

Like the NIDD, the National Physical and Sensory Disability Database (NSPDD) is a service planning tool that aims to provide a profile of people with physical or sensory disabilities who are receiving specialised health and personal social services and who are waiting for specialised health and personal services. Data is collected for service users who began their usage before the age of 66 and it currently has over 20,000 registrations. An important

feature of the NSPDD is its incorporation of International Classification of Functioning concepts into the administrative form. This ensures that data is collected on important life areas such as education, as well as salient contextual factors that impact on impairment. The Long-Stay Activity Statistics reports annually on the number of people in statutory long-stay care facilities and in private nursing homes. Data is categorised by age, medico/social status and level of dependency.

No comprehensive statistics exist for people with mental health difficulties. Usage of acute services is reported under the National Psychiatric In-Patient Reporting System maintained by the Health Research Board, however no equivalent service database that covers community-based treatment and support exists for people with mental health difficulties.

It is evident from the above that there could be questions about the extent to which the administrative databases reflect the full picture of needs for people with disabilities. Even the most complete of the three, the NIDD, does not take account of people with intellectual disabilities who, for whatever reason, have not come in contact with formal services. Participation in the databases is also a major issue affecting their reliability. A recent report on the NPSDD showed participation in some areas as low as 12%, while in other areas it was as high as 86% (O'Grady unpublished). The extent to which such databases can capture the full demand for services, and thus can be effective planning tools, must be of concern. In addition, it would be important for all health information datasets to be equality proofed to ensure that the data fully reflects the situation for people from disadvantaged as well as mainstream groups.

### **European Countries**

The measurement of health status and disability prevalence in European populations has attracted attention at a cross-European level only since 1997 when Article 13 of the Treaty of Amsterdam gave the EU competence to deal with discrimination. The reference to non-discrimination in relation to disability accelerated co-ordinated approaches to measurement. However the majority of published work concentrated on people aged less than 65 years in line with European Union prioritisation of employment policy. According to Meltzer (2000) the rationale behind the incorporation of a disability module in the Labour Force Survey is 'to meet the need for a comprehensive and cohesive dataset on the labour market situation of disabled people among Member States' (Meltzer 2000, p. 3). Meltzer describes disability data in the context of employment as opposed to disability and ageing generally. Malo

(2001) provides an analysis of the employment status of people with disabilities using the European Community Household Panel Data. This provides an analysis on participation and non-participation rates of people with disabilities in the labour market and does not attempt to confront issues regarding the population over the working age of 64 or over.

Most countries use several systems of classification and definitions of prevalence to cover a variety of circumstances governed by different Ministries or Government Departments. Examples are definitions used for social security and social assistance entitlements (social protection), employment and restrictions or supports in the labour force, legislative definitions, or health related issues to address health and medical needs of an ageing population. As a consequence there is no single agreed prevalence picture at national level in most countries. There is simply the prevalence data generated by specific definitions of disability/health status for a range of policy objectives and eligibility criteria. The European Commission (2002 and 2004) provides an overview of the definitions of disability of member states in the EU as well as Norway which are the definitions used in anti-discrimination laws in the respective countries. The anti-discrimination laws focus on the act of discrimination rather than the health status of the person.

Sharing an understanding of data issues has increasingly been facilitated by Eurostat. Grammenos (2003) highlights Eurostat (2001) data that outlines the prevalence of chronic illness or disability by age group in the EU and includes the 64 to 94 age groups. He discusses age and disability and states that chronic illness and disability tend to occur at an increasingly greater age with each generation. Repeated events (sickness, accidents) during adult life accumulate and generate the need for long-term care of the elderly and the author concludes that this does not mean that chronic illness and disability among the elderly is merely a consequence of chronological age - income, education, lifestyles and work are strong influences on health. Grammenos uses data from Nososco (2001) and discusses early retirement and older people with disabilities in terms of the age groups defined across Denmark, Finland and Sweden. The Commission (2001) examined ECHP data between work age cohorts of 16 - 64. The European Commission states that the clearest and most consistent relationship across countries is between age and disability. Higher age groups have higher disability rates as evidenced in Germany, Greece, Italy and Spain. In England and Wales, data collected between 1989 and 1994 on people aged over 65 showed a greatly

increased prevalence of disability in the very old population, particularly women (AIHW 2000 citing Parker, et al., 1997).

### **Australia**

Australian statistics are much more comprehensive than those currently available in Ireland. The Australian Bureau of Statistics (ABS) has conducted a number of national disability surveys, health surveys, surveys of mental health and well being of adults as well as surveys of time use (this latter provides relevant information on, for example, the use of time for personal care and voluntary work). In spite of all the data available, the Australian Institute of Health and Welfare (AIHW) points out that there are limitations. In particular, it is difficult to make comparisons between population data and what it calls “administrative data” and between different administrative collections. The purposes of the data collection are many and varied and the definitions used vary. The surveys involve self-reported information on disability and health. Administrative data is mainly concerned with quantifying the numbers of recipients of services, and is produced by service providers. AIHW highlights how people with early onset disabilities may remain unknown to disability service providers until they begin to require services in later life (AIHW 2000). Carey, Cole and Boldy (2002) point to a lack of longitudinal monitoring of disability impact, and a failure to collect data reflecting people with multiple disabilities.

### **Ageing Data in Ireland**

Like disability data, information on ageing in Ireland is also available from a number of national surveys and datasets maintained on behalf of the Department of Health and Children and other service providers. Important examples include the Census and Ireland's main labour force survey, the Quarterly National Household Survey (QNHS), both of which are undertaken by the Central Statistics Office (CSO). In addition, useful data is provided by the Annual Health Statistics published by the DoHC, the Hospital In Patient Enquiry Scheme (HIPE), the two disability databases maintained by the Health Research Board and the Survey of Lifestyles, Attitudes and Nutrition (SLAN). As well as the current data that is provided in Irish sources, an increasing emphasis on long term planning has ensured that additional data has been made available, which projects the changing nature of Ireland's older population. The NCAOP published such a study, **Population Ageing in Ireland: Projections 2002-2021** (NCAOP 2004), which analyses ageing population projections at national and county level across the state.

A huge increase in the number of persons aged over 65 living in the state in 2021 compared to 2002 has been projected and was highlighted earlier in this paper. Furthermore, the counties with the highest projections of increases are all found in the western half of the country, although in terms of absolute numbers, almost one quarter of all males and females aged over 65 will live in Dublin county and borough in sixteen years time. In addition, it is predicted that a marked shift will occur in relation to the marital status of older persons. In particular, it is projected that the numbers of married and separated people in this age category will increase significantly, compared to the current dominance of single and widowed persons. Finally, an additional projection estimates that the number of old people living alone will increase substantially from 114,000 people in 2002 to 211,000 by 2021 (NCAOP 2004, p.2-3).

Such substantial changes in the nature and numbers of old people living in the state makes the case for accurate and reliable information on the current situation of old people all the more important. However, currently there are significant deficiencies evident in datasets. The NCAOP's conference paper **The Older Population: Information Issues and Deficits** (2005b) highlights the lack of person-centred data. The NCAOP argues that "the kind of data that is gathered for the main datasets reflects mainstream concerns with labour market participation" (NCAOP 2005b, p.36). The National Physical and Sensory Disability Database excludes those whose disability arises from age 66 onwards. Current datasets do not provide information on the causes of the increasing occurrence of impairment in old age. There is also lack of integration between datasets for different services, for instance between the Hospital In-Patient Enquiry Scheme (HIPE) and the Long-Stay Activity Statistics. Overall, there is a lack of population-based systems and registers to generate information on older people with disabilities. The datasets which are available operate as 'islands of information', tracking activities and events rather than individuals. There is also a need to distinguish between different groups within the older population, and to disaggregate age categories rather than utilise a single band of 65 years and over. (NCAOP 2005b, pp.37-38). Implementation of the Disability Act 2005's needs assessment and reporting provisions may provide a more coherent data collection system than exists currently.

Although there are limitations in national datasets, the NCAOP has conducted a number of studies about older people in Ireland. **Health and Social Services for Older People** (2001) reports results of a study into older people's views of their health and social service needs.

**Population Ageing in Ireland: Projections 2002-2021** (NCAOP 2004) analyses ageing population projections at national and county level across Ireland. There is a large number of other reports published by the NCAOP covering specific information on the situation for older people in Ireland.

### **Summary of Key Points:**

It is evident from the above discussion that considerable knowledge gaps remain about older people with disabilities in Ireland. This situation parallels, to some degree, that of other European countries. However, the gaps in statistics about people with disabilities are considerably worse in Ireland than elsewhere.

### **Key Points**

- Currently there is no agreed definition of disability as a basis for data collection. Definitions differ between services within a country, between services, legislation and survey research, and between countries. Developments are underway to improve this situation, including the upcoming National Disability Survey 2006 in Ireland, and the Measuring Health and Disability in Europe project.
- Most data collection on disability is focussed on the working-age population and thereby excludes older people.
- Service usage data is likely to under-represent disability prevalence and, due to poor participation rates in some areas, understate demand.
- Information on people with mental health difficulties is particularly sparse due to the lack of a dedicated person-centred administrative database.
- Datasets in Ireland operate as 'islands of information', tracking activities and events rather than individuals. For people with overlapping conditions of ageing and disability, administrative boundaries in data collection may hinder a comprehensive picture of their needs.
- Datasets should be equality proofed to ensure that they reflect the diversity of the ageing population.

## Chapter Four: Current Situation in Ireland

### Rights

In Ireland the intersection of rights for people with disabilities and older people occurs within national equality legislation and in the Disability Act 2005. The Equal Status Acts 2000 to 2004 and the Employment Equality Acts 1998 and 2004 give protection against discrimination on the basis of age and of disability. The Equality Authority works on behalf of both groups in promoting equality, and has produced key policy documents for each, including **Implementing Equality for Older People**, as well as guidance on implementing equality such as **Towards Age Friendly Provision of Goods & Services** and **Reasonable Accommodation of People with Disabilities in the Provision of Goods and Services**. This suggests that building on existing joint working between the NDA, the NCAOP, the Equality Authority and the Human Rights Commission may prove productive for progressing the common equality and human rights agendas of these two groups.

The other main piece of legislation affecting older people with disabilities is the Disability Act 2005. The Disability Act is part of the Agreed Programme for Government and a commitment in “Sustaining Progress”. It is a key part of the National Disability Strategy being put in place by Government to underpin the equal participation of people with disabilities in society. The provisions of this legislation are intended to build upon the existing equality legislative framework and are available in addition to equality and human rights legislation.

The Act enables provision to be made for the assessment of health and educational needs for people with a disability. In the Act, disability is defined as follows: “disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.” The inclusion of participation in social and cultural life as well as the economy means that those with retired status are not precluded from the definition and therefore may come within the scope of the legislation. Part 2 of the Act provides for an independent assessment of need, an individual service statement, and redress. With regard to the provision of this Part, the Minister for Health and Children may fix different dates for implementation for different

age categories. This means that the commencement dates for Part 2 with regard to older people may be earlier or later.

Section 3 imposes a duty on public bodies to make public buildings accessible, as far as practicable, by 31<sup>st</sup> December 2015. This will be of benefit to people of all ages with impairments, including those who have not reached the threshold to come under the definition.

Another element of the Government's National Disability Strategy is the Comhairle (amendment) Bill. The Comhairle (amendment) Bill puts in place personal advocacy services, specifically for people with disabilities who have difficulty obtaining, without assistance or support, a social service. This has the potential to improve access to services for older people.

It can be seen that a range of rights legislation is available in common for both older people and people with disabilities which can improve their participation in Irish society. Implementation of such rights depends partly on effective awareness-raising, a process which can be supported by organisations such as the NDA, the NCAOP, the Equality Authority and the Human Rights Commission.

### **Health Service Provision**

Historically, services in Ireland have been organised around distinct client populations of older people, people with physical/sensory disabilities, people with intellectual disabilities and people with mental health difficulties. This category division persists in the new structure of the Health Service Executive, which assigns responsibility for these groups to three different "Care Group Managers". The divisions are underpinned by separate budgets for each group. Separate funding militates against boundary-crossing of both professionals and clients, and creates a variety of difficult situations for older people with disabilities. For example, currently people with intellectual disabilities under 65 who develop dementia have no clear provision within the services. While the Psychiatry of Old Age professionals have expertise in dementia, they have no responsibility for services to this group (Wrigley & Loane 2004, p.36). On the other hand, people who have had long-term contact with the disability services may continue to receive services within the disability sector after the age of 65. The extent to which their needs as older persons are being met within these settings is unclear.

The division between categorised client groups is also evidenced in the current disability sector co-ordinating committees. These advisory committees are chaired by the Director of Disability Services, with representation from Heads of Discipline of disability service provision, voluntary sector disability service providers and people with disabilities. In general there is no representation from older services. This despite the fact that, as stated at the start of this paper, older people represent 42% of the population with disabilities.

Services for older people in Ireland have historically been oriented around acute services, with very little provision for care in the community. O'Neill and O'Keefe (2003, p.1282) report that health and social services for older people were relatively poorly co-ordinated; the number of specialists was low by international standards, and older people were increasingly reliant on fully-subsidized beds in acute hospitals. Relative to other countries, community care services have been underdeveloped. For example, in 1993, only 3.5% of the Irish population used home help, compared to 14% in Northern Ireland and 19% in Sweden. As of their publication, there was also virtually no access to speech therapy, clinical nutrition or social work (Ibid., p.1284). Funding and staffing levels for older people's services has increased in recent years, and innovative programmes have been initiated such as the ERHA's HomeFirst programme and Slan Abhaile project, both of which aim to support older people to remain in their homes. However, evidence is not available as to the extent of unmet need for community care services.

In the mental health services, older people with pre-age 65 mental health difficulties are routinely discriminated against. The Inspector of Mental Health Services states that it is "common practice in most mental health services for the elderly to exclude people who have attended the general adult mental health services in a given period prior to referral" (MHC 2005, p.118). She has expressed concern that these exclusions are depriving significant numbers of elderly patients from appropriate care. She also cites numerous examples of poor quality care for long-stay patients in mental health wards, including the absence of care plans, activities, or any evidence of therapeutic direction for patients in certain locations (Ibid., pp.144, 154). In addition, elderly long-stay residents of psychiatric wards are being discharged to private nursing home beds and other settings that are unapproved for mental health care (Ibid., p.118).

The picture which emerges in Ireland is one where the organisation of services on the basis of client groups, e.g. older people, disabled people and people with mental health difficulties,

creates barriers to receiving appropriate, person-centred care and support.

The Government's Health Strategy, Quality and Fairness – A Health System for You, makes a commitment to a 'holistic approach' to the planning and delivery of care, and to a co-ordinated action plan to meet the needs of ageing and older people. A key issue, then, for future policy must be the development of mechanisms, protocols and funding which allow for cross-cutting, co-ordinated and integrated care for individuals on the basis of a holistic assessment of needs, not on the basis of membership of a client group.

### **Health & Welfare Entitlements**

Entitlement to many of the services which are relevant to older people and people with disabilities is discretionary. The provisions of the Disability Act 2005 apply to all people with a disability, but its provisions relating to needs assessment can be brought into force at different times for people of different ages. Everyone over the age of 70 is entitled to a medical card; this universal entitlement does not exist for people with disabilities aged between 65 and 70. Comhairle 2004 highlights problems with the current entitlements. For example, a couple aged 65-70 whose only income is an Invalidity Pension has an income above the current income guidelines. There is considerable confusion and lack of clarity about who is entitled to free or subsidised long-stay care (Mangan 2003).

This situation has yet to be clarified by the Department of Health. Receipt of community care services such as community nursing and home helps is discretionary. The provision of aids and appliances such as walking aids and wheelchairs is also not clear-cut. The Mobility Allowance is not payable to anyone whose mobility problems start after the age of 66.

A significant issue arises regarding the difference in access for people with early and mid-onset impairments versus people who acquire impairments after age 65. Given the low rate of participation in employment of people with disabilities of working age, it is less likely that people with disabilities will have access to private health insurance to fund their care needs. In practice, this means that most people with early-onset disabilities are entirely dependent on the state health services, whereas people with disabilities arising in old age may be able to avail of private medicine. In addition, people with disabilities are less likely to have paid PRSI and are therefore less likely to qualify for contributory payments. The lack of employment status of people working in sheltered workshops and their equivalent means that they never qualify for the usual benefits available to workers. Finally, in general women, who make up the majority of the 'oldest old' people with disabilities, have less work-based

entitlements and pension arrangements than do men, given less continuous participation in work. Again, this suggests that women with disabilities will be more dependent upon statutory services than men.

There are separate income maintenance payments for older people and people with disabilities. Two of the main weekly payments for people with disabilities – Disability Allowance and Disability Benefit - cease to be payable at age 66. Invalidity Pension and Blind Person's Pension are payable after age 66 but from that age they are indistinguishable from Old Age (Contributory) Pension and Old Age (Non-Contributory) Pension respectively. The Household Benefits Package is available to all older people and to recipients of Disability Allowance and Invalidity Pension regardless of age. Social welfare payments to those over 66 are generally higher than those payable to persons under 66. People aged over 80 get an extra payment. The automatic entitlement of all over 70s to a medical card can also be seen as a recognition of the extra costs of ageing. The extra amounts payable to people aged 66 and over are not specifically related to the extra costs of ageing and there does not seem to have been any objective assessment of what those extra costs are or if the extra amounts bear any relationship to those extra costs.

### **Housing & the Built Environment – the Irish Context for ‘Livable Communities’**

The 1996 Commission on the Status of People with Disabilities identified access to the built environment as a key factor in enabling full participation of people with disabilities, and devoted an entire section of its report to this issue. It recommended instituting a policy of Lifetime Adaptable Housing. This recommendation has yet to be adopted. An NDA survey published in 2004 on social participation found that over 30% of homes in Ireland are not accessible (NDA 2004b).

As part of the assessment of housing need, older people and people with disabilities are listed as separate categories (Fahey and Watson 1995). Fahey and Watson suggest that physical illness or disability is the factor most likely to lead to special housing needs of local authority applicants for all household types. In its 1999 submission to the NESF on housing, the NCAOP reported a 10 percent increase in the number of households headed by an older person identified as in need of Local Authority housing between 1996 and 1999 (NESF 2000, p.88).

It also expressed the following main concerns:

- the lack of provision of social housing for older people
- the lack of support services for older residents of social housing
- the lack of attention to design features which are necessary as a result of the mobility problems some older people experience

The latter two issues, in particular, are common for people with disabilities of all ages.

In addition to Lifetime Adaptable Housing, older people with disabilities also need an accessible environment in order to enable their continued inclusion within their local community. In Ireland, the Building Control Act 1990 provides the legislative framework for the development of the built environment. The Part M regulations require that access to all new non-residential buildings should be 'adequately' provided. With reference to housing, Part M requires that all new dwellings be 'visitable' by people with disabilities. Responsibility for ensuring compliance with Part M rests with owners, designers and developers of buildings. The NDA is currently carrying out research into the effectiveness of the Part M regulations. Preliminary findings from the research suggest that the monitoring for compliance with Part M is poorly co-ordinated, haphazard and piecemeal. The findings also suggest that Part M has not improved access to the built environment for many people with disabilities. (NDA 2005c) The Irish Government has announced plans to amend building control legislation in order to strengthen enforcement. The proposed legislation includes introduction of a Disability Access Certificate for all new buildings and a simplified means of redress. In addition, the Disability Act 2005 includes further requirements for compliance with Part M by public bodies. Section 25 of the Act requires specified public bodies to ensure that their public buildings are, as far as practicable, accessible to persons with disabilities by 31<sup>st</sup> December 2015.

Other initiatives which are having a positive effect on the built environment include the implementation of the Barcelona Declaration (1995) and the Public Service Accessibility Initiative (PSAI). In 2001 the Irish Government established a project to implement the Barcelona Declaration amongst local authorities. The NDA was assigned responsibility for facilitating this process. The majority of local authorities have now endorsed the Declaration, and thereby made a commitment to 'adopting measures towards the necessary adaptation of urban spaces, buildings and services of all types, in order to allow full use by disabled

persons'. Under the PSAI, an Excellence Through Accessibility award has been developed which is based on the highest standards of accessibility, and which will recognise improvements in public service accessibility. The Excellence Through Accessibility award was launched in 2005. Finally, Section 52 of the Disability Act 2005 provides for the establishment of a 'Centre for Excellence in Universal Design' within the NDA. The Centre will contribute to the development and promulgation of standards of excellence in universal design.

### **Caring, Long-Term and Long-Stay Care**

Traditionally, most care for people with disabilities and older people has been carried out by women from the home. In terms of long-term care, Ireland has the second lowest expenditure on long-term care amongst 19 OECD countries (OECD 2005). This suggests that the system remains heavily reliant on informal care. The population of the "oldest old", people aged eighty years and over, is projected to increase three-fold in the next thirty years, to over 300,000 (NCAOP 2005b, p.10). The 2002 census shows that 34% of people over age 75 are living alone in private households. It is likely that a significant number in this group receive substantial informal care. Given current trends towards women working, and the likely increase in the population of the oldest old and of older people with long-standing disabilities, demands for formal care will increase substantially over the coming years. On the other hand, the structure of formal care is likely to change, as recipients of care push for more user-controlled, home-based supports to enable them to live independently in the community. The response to demographic and labour force changes, then, in responding to increased demand, should re-orient itself towards community-based, user-controlled support, rather than replicating existing structures of care. A re-structured care system also requires a partnership approach between older people with disabilities, families, statutory agencies, the voluntary sector, the private sector and local communities (NCAOP (2005c), p.7). Current developments regarding standards in long-term care are to be welcomed. The Social Services Inspectorate is working on the development of an inspection system for public and private residential care for older people, and the Irish Health Services Accreditation Authority is working on the development of accreditation standards for residential care.

The NCAOP has made specific recommendations on the financing of long-term care (NCAOP 2005c). The Council emphasises the need to provide a continuum of care, of

which long-stay care is a part. Long-term care is generally defined as assistance with instrumental activities of daily living and activities of daily living, whether provided in a residential or domestic setting (p.5-6), whereas long-stay care refers specifically to residential care. The NCAOP's submission divides care needs into self-care, community-based care, care and case management and long-stay care. In evaluating care needs, it is important to consider both health and social care dimensions of care (p.4-5). They define essential care needs as: personal assistance, home help services, meals on wheels, day care and respite care, allied medical services, and intermediate housing including sheltered housing (p.7). In light of the evidence outlined above regarding the high incidence of mental health needs amongst the older population, the NDA also believes it will be vital to provide community-based mental health services and supports as an essential service. The NCAOP supports the financing of long-term care through a modified social insurance scheme (p.8). The NDA points out that such a scheme should not be confined to PRSI-eligible people, which could potentially exclude people with lifelong disabilities who had not worked, and women whose years spent working in the home left them without sufficient PRSI cover in their own right (NDA (2005b)).

The NCAOP's submission quotes important OECD findings about the overall costs of long-term care. Long-term care costs are very sensitive to disability trends; postponed onset of disability reduces costs (NCAOP (2005c), p.13). Incorporating a social model of disability into this analysis means that by improving the built environment, enabling accessibility through assistive technology and providing adequate personal assistance, the costs of long-term care can be reduced.

One process that can assist with preparing for ageing is what is sometimes referred to as 'permanent planning'. Preparing person-centred care transition plans helps to minimise the negative consequences of transitions in support arrangements. This issue arises in particular for those people with intellectual disabilities who live the majority of their lives at home with support from their parents. Reilly & Conliffe's work on future planning for ageing adults with intellectual disabilities argues for incorporating quality of life issues when planning around residential transitions. Their research also highlighted, amongst the carers surveyed, a lack of awareness of the need for future planning. About half of the respondents indicated that registration on the Intellectual Disability Database was "tantamount to a concrete future plan"

(Reilly & Conliffe 2002, p.113). Such evidence indicates a lack of both recognition and adequate planning for the growing population of older people with intellectual disabilities.

### **Capacity**

An area where there are common issues for both people with disabilities and older people is that of capacity for decision-making. The Law Reform Commission has recently published its consultation document on vulnerable adults and capacity. The document aims to review the issue of legal capacity for vulnerable individuals over 18 in a range of decision-making areas, including the areas of capacity to enter into a contract, capacity to enter into relationships and capacity for healthcare decision-making (LRC 2005). The NDA and the NCAOP look forward to informing the development of new legislation on capacity and its associated provision and practice. While there are commonalities in the appropriate legislative framework for both groups, the differences in the situations of people with incapacity or limited capacity in early and mid-life versus those in later life will also need to be addressed. For example, the disability movement has emphasised the need for independent advocacy in interactions between people with disabilities and statutory bodies. This suggests that people with disabilities may be less inclined to favour familial guardianship for assisted decision-making.

### **Summary of Key Points:**

- Older people with disabilities in Ireland have common rights under equality, human rights and disability legislation. Future joint working between older people and disability organisations could be valuable in progressing the effective implementation of these rights.
- Services in Ireland are organised around distinct client populations; this creates barriers for people who may be impacted by situations of both ageing and disability.
- There is evidence of discrimination against older people in some health services.
- There is lack of clarity around the entitlements of older people.

- People with early and mid-onset disabilities may be disadvantaged in an entitlement system based on long-term labour force participation.
- Similarly, women with disabilities may be disadvantaged in an entitlement system based on long-term labour force participation.
- Deficiencies in enforcement of Part M building control regulations have hindered improvements in the built environment which could enable 'livable communities' and 'ageing in place' in terms of universal access and Lifetime Adaptable Housing. Measures such as the Disability Act 2005 provisions on access to public bodies, proposed improvements to the enforcement provisions of Part M, continued implementation of the Barcelona Declaration, and the establishment of a Centre for Excellence in universal design may improve Ireland's built environment in the future.
- The care system relies on widespread provision of informal care; developments should re-structure care provision around community-based, user-controlled support to enable independence and ageing in place. The financing of long-term care should not discriminate against people with early and mid-onset disabilities.
- People with disabilities and older people may experience impairment in their capacity to participate in decision-making; this common concern suggests scope for joint working on establishing assisted decision-making systems. Assisted decision-making must respect the preferences of people with disabilities for independent advocacy.

## **Chapter Five: Policy Implications**

### **Ageing with a Disability and Disability with Ageing**

It is perhaps ironic that despite the statistical overlap between older people and people with disabilities, there has been little joint working between the two groups. The literature on ageing and disability has increasingly recognised a distinction between the ageing experience of people with early-onset disabilities and the experience of older people who develop impairment in later life (Hasler 1991, Verbrugge 2002). According to Verbrugge, “people who incur disability at birth or in childhood are said to ‘age with disability’, and those free of disability until mid- or late-life are said to experience ‘disability with ageing’” (2002, p.1). The fact that services for people with disabilities and older people are segregated exemplifies this distinction.

### **The Argument for a Distinct Strategy**

A number of commentators argue that there are distinct issues for people with early-onset disabilities. People who enter the ageing process with a disability may have their primary identification as a disabled person already firmly established (Gilson & Netting 1997, p. 292). They may have different life experiences from non-disabled people: fewer social supports, lack of an employment history, few assets for retirement, and [in some cases] pre-existing high dependency (Bigby 2002, p.232). People with disabilities often age within a service system rather than external to it (Bigby 2004, p. 244). For highly dependent people with disabilities, the loss of parental carers in mid-life will be a significant factor. Bigby concludes that “the pertinent issues in aged care are largely irrelevant to people ageing with a disability” (*Ibid.*, p. 244).

Conversely, older people often choose the ageing community as a primary identification, rather than the disability community (Priestley & Rabiee, 2002, p.605). Since impairment is seen as a normal part of ageing, older people do not tend to see themselves as disabled (Priestley 2003, p.155). Some writers even suggest a conscious effort on the part of ageing advocates to distinguish disability from ageing (Kennedy & Minkler 1998, p.758).

Bigby (2002), whose work largely focuses on people with intellectual disabilities, argues for adopting a specific focus on people who are ageing with a lifelong disability. In her most recent work, she recommends a distinct set of policy directions for people ageing with a disability. These include realising the overarching principles of equal rights, choice and self-

determination, the adoption of a leadership role by disability services, and systematic bridging of gaps between services (Bigby 2004, p.255).

### **The Argument for a 'Common Agenda'**

Other researchers have argued for a 'common agenda' between the disability and ageing communities. The interest in independent living and consumer-directed services by the ageing sector in the USA has led to discussion of a 'common agenda' (Rusinowitz 1999). A key focus of this common agenda is the development of consumer-directed services, primarily personal assistance services (Ibid., p.2). As previously discussed, an increasing number of ageing community providers in the USA are supporting more consumer choice and control in services (Ibid., p.3). Their desire to reduce costs for care for the ageing population is leading them to incorporate service orientations from the disability sector. In the UK, Priestley & Rabiee identified an extensive list of issues around which there is common ground for political alliances between the two groups (Priestley & Rabiee 2002, p.603).

The common status both groups enjoy under Ireland's equality legislation, as well as common principles apparent in international human rights legislation, provide a basis for solidarity around equal and human rights. Clearly there is scope for joint working between ageing and disability groups on common issues of concern. In addition, the following policy initiatives are relevant to both groups and offer opportunities for collaboration.

### **Person-Centred Planning**

Person-Centred Planning offers a service orientation framework that facilitates changes over the life course. The NDA's publication **Person-Centred Planning in the Provision of Services for People with Disabilities in Ireland** (2005a) describes the elements of this approach. Based around developing a life plan for the individual, Person-Centred Planning is flexible and responsive to changing needs, grounded in a social model and a strengths-based approach and takes into account the wider network in terms of support and of needs. This makes Person-Centred Planning particularly appropriate for managing life transitions. It focuses disparate services around the holistic needs of the person, and recognises the needs of the wider family network (NDA 2005a). The NCAOP has long advocated person-centred care (see Delaney, et al. 2001), and has recently reiterated this by calling for long-term care that is oriented around the needs of the individual (NCAOP 2005c, p.16). The NCAOP argues that the role of assessment is the cornerstone of long-term care, and that

such an assessment should be 'holistic, person-centred and encompass medical, social, psychological and financial domains' (Ibid., p.17-18). Policy guidance by both the NCAOP and the NDA thus advocates a move towards person-centred provision.

### **Creating 'Livable Communities'**

The National Council on Disability (NCOD) in the USA cites the key factor in the successful implementation of 'living communities' as the formation of strategic partnerships (NCOD 2004, p.129). They highlight the example of the San Mateo Strategic Plan, where several agencies joined together to create a strategic plan which would address the needs of both older people and people with disabilities. Implementation of the strategy depended on consolidating administration between disparate agencies, using incentives to stimulate changed behaviour in individuals and corporate entities, providing funding which encouraged integrated, consumer-directed and community-based services, and accessing public-private partnerships (NCOD 2004, pp. 130-132).

In Ireland, the move to community-based services for people with disabilities will help to bring about 'livable communities'. So too, implementation of the access provisions of the Disability Act 2005, improved enforcement of building control legislation, and other developments such as creating accessible transport have a major role to play. There exists a need for further intervention in the area of housing to ensure both people with disabilities and older people have the maximum opportunity to reside in their local community. Developments would be greatly aided by a coherent and comprehensive National Disability Strategy. Council and Community Development Boards could also play a key role if, in addition to implementation of the Barcelona Declaration, the goal of creating 'livable communities' was incorporated into their strategic plans.

### **User-Directed Services**

In Ireland no initiatives have yet been undertaken to provide user-directed services. As reported above, user-directed services have been implemented in the USA, Germany, Austria, France and the Netherlands. Some countries provide cash benefits to users to pay for services, others provide a budget for each user. If a comprehensive needs assessment system for people with disabilities in Ireland is implemented, on foot of the Disability Act 2005, this may provide the administrative basis to enable user-direction in Ireland. This suggests that such a system would be implemented through the Department of Health & Children. Further detailed exploration of the administrative requirements is needed in order

to enable its implementation here. In addition, lessons need to be learned from the experiences in other countries. Issues such as how service users can be supported to manage services effectively, how to ensure quality and accountability in services, how to develop a well-trained labour force of personal assistants and other workers, and how to protect against fraud and abuse all require consideration (see Simon-Rusinowitz, et al. 2002 for further discussion).

### **Integration & Co-ordination Between Service Sectors**

A key question on the ageing and disability agenda must be how to ensure effective integration and co-ordination between the service sectors for older people and people with disabilities. In the United States, integration and co-ordination was driven legislatively. Amendments to the Older Americans Act and the Developmental Disabilities Act in 1987 mandated access to generic aged services for older people with disabilities and collaboration between the two service systems. At the same time, co-ordinated policy was supported by the establishment of several university-affiliated programs for developmental disabilities and by the establishment of the Rehabilitation Research and Training Centre Consortium on Ageing and Developmental Disabilities (Bigby 2004, p.250).

In Ireland, lack of co-ordination between Government departments has already been raised as a difficulty with policy implementation in disability services. Decisions need to be made so that both options of 'ageing in place' and inclusion of people with disabilities in mainstream ageing services are provided. Such decisions should be guided by the expressed preferences of older people with disabilities.

### **Options for Further Action**

1. Discussion between all stakeholders to define the common and the distinct agenda for older people and people with disabilities. This discussion could clarify the drivers of change in policy for older people with disabilities, e.g. economic, service, and/or social change.
2. An initiative to develop a national ageing and disability policy framework could be established. Elements of the framework could include a data strategy, clarification of the rights of both groups, integration and co-ordination of services, delineation of the

needs of people ageing with disabilities and people with disabilities acquired in ageing, and recommendations on implementation.

3. Research could be undertaken to assess the holistic needs, including health, housing, transport, income, education, environmental, social and cultural needs, and desires of older people with disabilities. Such research should distinguish between people with early, mid and later-life onset physical, sensory, intellectual and mental impairment. Research should also reflect the experiences of women with disabilities, people with disabilities from different ethnicities, people with disabilities from the Traveller community, and people with disabilities with different sexual orientations.
4. A scoping exercise on legislation could be undertaken with two objectives: firstly, to evaluate the effectiveness of existing equality and human rights legislation for older people with disabilities; and secondly, to identify areas where new legislation would be valuable to improve the social inclusion of older people with disabilities. Research should also be undertaken to describe the distinctive rights concerns of women with disabilities, people with disabilities from different ethnicities, people with disabilities from the Traveller community, and people with disabilities with different sexual orientations.
5. Mapping research could be useful to track the path of individuals with early, mid and later-life onset disabilities through the health, housing and social services.

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