

## **In-house Report 137**

# **INDEPENDENT LIVING IN LATER LIFE: LITERATURE REVIEW**

*INDEPENDENT LIVING IN LATER LIFE: LITERATURE  
REVIEW*

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**A report of research carried out by the Oxford Institute of Ageing, University of Oxford on behalf of the Department for Work and Pensions**

**August 2003**

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## 1 BACKGROUND AND INTRODUCTION

The Institute of Ageing at the University of Oxford (OIA) was commissioned by the Department for Work and Pensions (DWP) to carry out this literature review on independent living in later life, which comprises a comprehensive but by no means exhaustive review of primarily but not necessarily exclusively UK and European literature on issues related to *independent living in later life*. The Government is committed to facilitating and promoting independent living for today's and tomorrow's pensioners, and the Department for Work and Pensions is developing a model of service delivery to promote independence and an active life for older people. The findings from the research will thus assist in the development of these policies and services.

### 1.1 Aims of the research

This literature review identifies UK, European and North American (and Australian) literature primarily from 1982, with a focus upon literature from 1990 which addresses a broad range of aspects concerning both research into independent living in later life, and policy developments and examples of good and bad practice designed to promote such independent living in later life.

The **aims** of the review were:

- to assess and synthesis existing evidence on the factors which affect older people's ability to live independently;
- to increase knowledge of interventions and policies which have facilitated independent living in later life;
- to identify gaps in research evidence on independent living in later life;
- to provide evidence to support the development of services which facilitate independent living in later life with specific but not exclusive relevance to the Department for Work and Pensions;
- to provide the context for research exploring the interrelationship between independent living, service access, and socio-demographic characteristics.

Furthermore, the review has sought to identify, appraise and synthesise more recent UK, European, North American and Australian evidence on

- older people's interpretation of independent living;
- factors facilitating and inhibiting respectively independent living in later life;
- the efficiency of interventions and policies designed to facilitate independent living in later life;
- factors impacting upon this efficiency.

The review has focused on literature related to social welfare but has also sought to include aspects such as public and voluntary services, economics, familial networks, housing, social care, health, empowerment, transport.

A key feature of the review work has been to elucidate different concepts of independence and different factor-prioritisation both on the part of the various research communities but also on the part of the various actors (older people, family members, public and voluntary bodies). Independence – very much along the same lines as quality of life – is a concept, which is not only difficult to define universally, it is difficult to assess and measure because of its individuality. Despite this, *independence* as a quality of life promoting phenomenon is often quoted as an issue of high priority for older people and for those working with and for older people. For example, the promotion of lifetime housing across Europe was seen as related to the policy of sustaining the independence of older people, who are living in their own homes though with increasing degrees of difficulty (Winters 2001). Frail older people have been defined in a research framework as being *dependent on the help of other people in relation to personal hygiene, care and daily life activities* (Christophersen 1999), but this definition should not per se exclude such older people from the concept of independent living.

*Independent living in later life* is clearly an area where the different groups involved around an older person (researchers, older people, policy makers, practitioners, family members, local authorities) frequently differ in their interpretation of the concept itself and therefore doubtless in the means of promoting the concept for individual older people. Thus, there is between and within group heterogeneity, and this is addressed in the work covered by the review.

In considering *independent living in later life* it has been important in the review work - in addition to acknowledging the individuality of independence – to be aware of the fact that elucidation of the concept may demand different research approaches dependent on the subsegments of older people being considered. For example, while a quantitative approach may be sufficient in relation to active older people, a qualitative anthropologically-based approach would be more suitable in relation to frail older people (Christophersen 1999). These distinctions in research methodology have been taken into account in the review process.

*Independent living* - and the potential for it - is dependent not only on the immediate socio-economic situation of an older person, it is also dependent on a variety of other factors: public and voluntary services (accessibility and availability), policy interventions to facilitate independent living, and life history (coping with ageing), for example. Add to this the fact that independent living will be interpreted differently by different older people – even those who may seem to have the same underlying characteristics – and understanding this interpretative process is an integral part of understanding the concept of independent living and thus comprises a key aspect of the research covered by this review. The review seeks to address the complex of factors contributing to independence in later life, including socio-economic and demographic status, living arrangements, health, activities, social and familial networks, life history of coping.

Bearing in mind this complexity, it is important to incorporate research, which has contributed to understanding the concept of *independent living* and the means by which it can be achieved. The review covered quantitative and qualitative research on:

- a. concept of independent living in different segments of older people as understood by the different segments, and refers both to past, present and future experience/perceptions;

- b. older people's experience of barriers to independent living and refers to past, present and future experience/perceptions;
- c. good and bad practice in enabling independent living for older people in the public and private sector;
- d. the efficiency of policy intervention aimed at enabling independent living for older people.

In addition, United Nations, European Commission and UK Government policy developments and information from national and European organisations working toward the promotion of independent living were included to set the research and future policy recommendations in a policy context.

## **1.2 Structure of the report**

The aims of the research, the sources of literature accessed (including websites), the methodology and the limitations of the review are briefly addressed in this chapter.

Chapter 2 presents policy statements and developments, beginning with the United Nations and the World Assemblies in 1982 and 2002 and touching upon the UN International Year of Older People, drawing out the main European Commission initiatives in recent years, and giving a more detailed but again not exhaustive overview of policy developments in the United Kingdom illustrating the emphasis on independent living in later life from the early 1950s to the present day. This policy overview is designed to set the scene for the review and provide a platform for future recommendations.

Chapters 3 and 4 form the main body of results of the literature review. Chapter 3 focuses on the definitions of independence and the factors found to influence and determine independence in later life from both an objective and subjective point of view. That is the objective view of the researcher, policy maker and practitioner, and the subjective view of the older person themselves. Chapter 4 explores how the various actors can support independent living of older people.

Chapter 5 presents a two-nation case study based on interviews with key people in each country either in terms of independent living alone or in terms of older people, their situation and policy developments generally. The countries chosen are Denmark and Italy providing an interesting geographical, cultural and welfare mix, which may influence the development of independent living in later life.

Chapter 6 presents policy recommendations based on the literature and outlines research areas, which could be explored further in depth in the future.

In conclusion, there is an extensive bibliography from the review, which has provided the material for the content of the report.

## 1.3 Research sources

### Scope of the review

Taking the work of the Oxford Institute of Ageing as its point of departure (Harper and Leeson 2002, 2002a), this review with regard to *independent living in later life* covers academic research carried out by university research institutes, local and central government research institutes and departments, and private (semi-public) research institutes across Europe. The review also includes policy overviews, policy statements and appraisals drawn up in consultation with older people by relevant national and European NGOs in the field of ageing and older people.

This approach provides the review with the required breadth, depth, and diversity to make it sufficiently comprehensive, within the limited time available.

Following an initial broad search of key words, the review search was focused on those which the researchers identified as having direct search bearing on the subject matter: independent living and active ageing linked into psychological aspects, models of independence, socio-economic and demographic status, housing, health, family relations, activities, social networks, life history of coping.

It should be underlined, however, that selected research work and the work of NGOs is not necessarily nationally representative. While especially national quantitative studies may give (representative) generalisations of use to policy makers and practitioners, more restricted (both quantitative and qualitative) studies will often elucidate specific issues of importance to local conditions and segments of older people, which may not appear from national studies in the same detail, if at all. It is hoped that individuality and heterogeneity is thus covered by the diversity of the extent of the work included.

In the broad archive search, the following data and information sources were utilised:

### Search engines

BIDS (Bibliographic Service for the Academic Community)

Web of Science (Science, Arts and Humanities Citation Index)

SOSIG (Social Science Information Gateway on sociology and social policy)

Cochrane Collaboration (Research resource with the aim of maintaining and promoting the accessibility of systematic reviews of the effects of healthcare interventions)

Medline (National Library of Medicine)

### Research Centres/Organisations

Kings College –ACIOG (Age Concern Institute of Gerontology)

Kings Fund (Independent charity, primarily working on health improvement)

CPA (Centre for Policy on Ageing – information services)

### Journals

BMJ online (British Medical Journal)

Ageing and Society (Journal of the Centre for Policy on Ageing and the British Society of Gerontology)

JSTOR (The Scholarly Journal Archive)

In addition, the following websites have been accessed:

European Commission Website;

[www.psi.org.uk](http://www.psi.org.uk) - the website of the Policy Studies Institute;

[www.policybrief.org](http://www.policybrief.org)

[www.milbank.org](http://www.milbank.org)

[www.spkweb.org.uk/howitwillwork](http://www.spkweb.org.uk/howitwillwork)

[www.doh.gov.uk/cos/older people/index.htm](http://www.doh.gov.uk/cos/older%20people/index.htm)

[www.Eurocentre.org](http://www.Eurocentre.org)

Across Europe, a number of researchers and policy makers have been contacted to supplement the information gathered from the archive and web searches. In addition, national and European organisations have been contacted and consulted with regard to their own initiatives in the field of independent living.

#### **1.4 Limitations of the review**

The obvious limitations relate to time available and to the scope of the archive and website searches, which in turn have been constrained by the keywords used to access and search databases. The nebulous nature of the concept of *independent living* means it is impossible to develop a set of keywords, which would be encompassing enough to exhaust the literature on independent living.

Time needed to secure less easily accessible work has also resulted in some – perhaps relevant – work not being included in the review report.

While the OIA team have fluent language skills in Greek, Danish, Swedish and Norwegian, and German, a full and comprehensive review of European literature was clearly not possible. The team suggest that this is an important component, however, and should be addressed by DWP in any follow-up work providing within the budget finance for translation.

#### **1.5 Methods**

In considering *independent living in later life* it is important to be aware of the fact that elucidation of the concept may demand different research approaches dependent on the subsegments of older people being considered. For example, while a quantitative approach may be sufficient in relation to active older people, a qualitative anthropologically-based approach would be more suitable in relation to frail older people (Christophersen 1999). These distinctions in research methodology have been taken into account in the review process.

This review, which is purely descriptive and based on an in-depth analysis of identified sources, focuses primarily on UK, European and North American (and Australian) literature over the last 15-20 years and includes both quantitative and qualitative research findings, policy documents and evaluations of practice. The research reviewed covers both older people's views on independence as well as elucidation of factors deemed to determine independence in later life. Just as the concept of independence is nebulous so too the definition of older people, and the research team has made no a priori attempt to define the group of older people, which in a transnational review such as this will be affected by the cultural norms of different nations.

The commissioning of an expert group at Oxford to carry out the review enabled the inclusion of not only articles from peer reviewed journals but also the independent peer reviewing of other material - working papers, chapters in books, reports, conference articles. Some 400 articles were identified, of which almost 200 were deemed to be of significant quality and relevance to be considered in the review. The final report focuses on these, of which a smaller number have proved particularly useful and are given as examples of data compilation charts.

Two OIA Working Papers (Harper and Leeson 2002, 2002a) provided an initial basis for the present review. These covered European material on policy, research and practise related to active ageing, social inclusion and independence up to 2001. These were reassessed and extended using a computer and personal search of both published and unpublished material.

The search has been carried out in a number of parallel, complementary ways. A computer and personal search of published material forms the basis for most of the work covered by the review. Searches of unpublished material have also been carried out, and researchers, policy makers and practitioners across Europe have been contacted with a view to obtaining not only otherwise inaccessible work but also the state of current thinking in the national settings. Not all of the material accessed has been peer-reviewed, but each piece of such work has been peer-reviewed by the OIA team before inclusion in the review.

Personal contacts have been made by e-mail with a two-week follow-up in the event of no initial response. As will appear from the section on other literature accessed in the work, much of the literature suggested by European contacts was not in English.

Various forms of literature were thus accessed on the basis of identified key words designed to cover the diversity of approaches to independent living in later life, and a number of these were subjected to more in-depth analysis of methodology, content and policy implications. The criteria for in-depth inclusion were validity, robustness, originality and relevance to policy.

The following **standard peer review criteria** have been used by the research team for appraisal of the work accessed in the field of *independent living in later life*:

1. the research is unbiased i.e. has a clear statement and hypotheses to be tested by the research and is free from culture-attitude based statements and conclusions not supported by the research;
2. the research methodology is robust and addresses the questions of individuality and heterogeneity mentioned above;

3. the research results have been published in peer-reviewed journals or edited publications or in terms of adjudged quality are of this calibre (peer-reviewed by the OIA team).

The third of these criteria means that working papers, articles published in journals without peer-review etc are not automatically excluded from the review. In addition, unpublished work where pertinent and accessible has been included in the review.

As far as overviews/policy statements by national and European NGOs are concerned, their unbiasedness cannot obviously be taken for granted. Nonetheless, such overviews/policy statements will provide important insights into the views and expectations and experiences of the organisations (and their members) even though not based on robust research approaches. In this respect, such work is felt to be an important and illustrative supplement to research addressing the views and expectations and experiences of older people themselves with regard to *independent living in later life*.

The broad-based search on the basis of the identified key words gives a veritable plethora of work. A structured assessment of this accessed work was based on the following procedures:

1. abstracts and summaries collected;
2. individual team members determine from the complete set the immediate relevance of each piece of work in line with key words and aims of the review;
3. complete piece of work secured;
4. work read and schematically summarised by individual team members;
5. work appraised for further study by the team;
6. work appraised in detail by individual team member.

Case-study interviews in Denmark and Italy were carried out face-to-face by the team's two senior members. No attempt to interpret or conclude from these interviews has been made by the team.

## **2. POLICY DEVELOPMENTS: UNITED NATIONS, EUROPEAN AND UK EXPERIENCE**

In this section, a brief and by no means exhaustive overview of policy developments in the field of ageing will be given, taking as its point of departure the International Plan of Action on Ageing of the United Nations, moving to examples of more recent European developments and concluding with the experience in the United Kingdom. In addition, organisational policy statements will be presented. The aim is to give both a historical perspective and a state-of-the-art, so to speak, in order to set the stage for the development of policy to support independent living in later life in the United Kingdom – an understanding of the past is an eminently sensible platform for shaping the future. It is indeed striking how central the concept of independent living – without being stated explicitly – is to policy statements and developments over the last two decades. At the same time, however, it is equally striking that not all suggested measures take the wishes of older people themselves into account. The policy statements and recommendations presented here are the sole responsibility of the organisations concerned and in no way reflect the result of any analysis by the research team.

### **2.1 United Nations**

The International Plan of Action on Ageing of the United Nations, adopted at the first World Assembly on Ageing in Vienna in 1982 guided thought, policy development and action on issues of ageing until the International Plan of Action on Ageing 2002 was adopted in Madrid. This called for changes in attitudes, policies and practices at all levels in all sectors in both the developed and the developing world with a view to fulfilling the potential of ageing in the 21<sup>st</sup> century. The aim of the 2002 Plan of Action is to ensure that *persons everywhere are able to age with security and dignity and to continue to participate in their societies as citizens with full rights*.

In addition, the UN International Year of Older Persons in 1999 contained four dimensions, which have clear relevance to independent living:

- individual lifelong development;
- multigenerational relationships;
- the interrelationship between population ageing and development;
- the situation of older persons.

A number of themes from the 2002 Plan of Action clearly support the concept of independent living:

- achieving secure ageing in financial terms;
- empowerment of older persons;
- provision of opportunities for individual development;
- elimination of age discrimination;
- recognition of the important role of the family;
- provision of health care, support and social protection;
- facilitating partnership between all levels of government, civil society, the private sector and older people.

It is emphasized in the 2002 Plan of Action, furthermore, that older persons should be enabled to continue to work for as long as they desire and are able. This should be promoted through

policies related to sustainable work-related health care services with the emphasis on prevention, promotion of occupational health and safety, and access to technology, life-long learning and flexible retirement arrangements. Disincentives to working beyond retirement age should be removed.

The importance of intergenerational solidarity is underlined as a prerequisite for social cohesion and a foundation of formal public welfare and informal care systems, and the value of intergenerational ties at the family and community level is recognized but with due account being taken of the fact that living with younger generations is not always the preferred or best solution for older persons. Equity and reciprocity between generations are seen as major factors to strengthen solidarity.

Advancing health and well-being into old age is seen as a priority direction for the coming decades, and the full access of older people to health care and services as well as recognition that health promotion and disease prevention need to focus on maintaining independence are acknowledged as important elements of this, along with a reduction of the cumulative effects of factors that increase potential dependence in old age.

## **2.2 European Commission**

Three Commission documents/initiatives seem pertinent to the area of independent living in later life and reflect European developments in parallel with UN developments, as should appear from the brief presentations below. A fuller discussion on European social policy may be found in Hantrais (1995) with relevance to older people discussed in Harper and Leeson (2002).

The first of these from May 1999 is a Communication entitled *Towards a Europe for all Ages – promoting prosperity and intergenerational solidarity*, which was the Commission's official contribution to the UN International Year of Older Persons in that same year. The Communication outlines the implications of the ageing population for employment, social protection, health and social services, and suggests that a strategy for effective responses in these fields should be based on strengthening co-operation amongst all actors and solidarity and equity between generations, thereby echoing the call of the United Nations. The Communication lines up several dimensions of the challenge of ageing societies:

- It calls for due attention to be paid to the long-term sustainability of public finances if intergenerational equity, that is equality between generations, is to be addressed, noting that a broader base for social protection systems must be secured with pension systems being made less sensitive to demographic (and other) changes.
- The development of formal care systems as the demands of a growing number of older people increase is necessary, and it calls for policies to curtail the growth in dependency through the promotion of healthy ageing, accident prevention and post-illness rehabilitation.
- Importantly, the growing diversity among older people in terms of resources and needs is acknowledged, and the effect of differences in family and housing situation, educational and health status and in income and wealth on the quality of life of older people is underlined.

In this respect, the continued risk of social exclusion and poverty in old age should not be forgotten and this diversity should be reflected in policy, which utilizes to a greater extent the resources available to large proportions of the older population. Gender issues and social protection are particularly striking, with the weak labour force participation of women, social protection systems based on male breadwinners, and gender differences in longevity leaving insufficient pension cover for many older women. The Communication's dimensions of the challenges of an ageing population led to the following four policy conclusions from the Commission:

- to develop measures to maintain workers' capacities, promote life-long learning and flexible working arrangements, as well as review tax and benefit schemes to improve incentives to work and train;
- to explore new forms of gradual retirement and to make pension schemes more sustainable and flexible;
- to give special attention to medical and social research related to ageing, and to support the development of adequate responses to ageing in health and care;
- to promote policies against discrimination and social exclusion.

It is interesting to note that the Communication concludes by stating that *the demographic development will force the European Union to rethink and change outmoded practices and institutions as an active society for all ages requires a strategy which both enables and motivates older people to stay involved in work and in social life*. This is a clear reference to independent living.

The second Commission document of interest here is its communication from October 2000 on *the future evolution of social protection from a long-term point of view: safe and sustainable pensions*.

- It is noted that no reasonable policy measures will be able to counteract the changing demographic structure of the European Union and that the economic dependency ratio rather than the demographic old age dependency ratio is what matters for the sustainability of pensions.
- Reforms to make pension systems sustainable are acknowledged as politically difficult and politically challenging, needing to achieve as large a consensus as possible and at the same time being comprehensive and not exclusive to pensions. There will need to be a balance between contributions and entitlements and between the active and the retired populations.
- It is pointed out that current pension systems tend to encourage early exit from the labour market, ignoring individual needs and often offering insufficient coverage for the most mobile and flexible members of the workforce. The incentive structure of pension schemes needs to be reviewed with a view to making them more employment-friendly.
- Although pensions ensure that older people enjoy reasonable living standards, there are still gaps in income provision for older people with poverty rates among older women especially higher than average. Granting pensions rights for bringing up children or providing care is therefore an important element of solidarity as are lower contributions for low-paid workers.

- Ageing populations aggravate these inadequacies. Any reform of pension systems needs to encourage older workers to remain in the labour force, a key component of independent living.

The third report from the Commission is the *report on social protection in Europe 1999* from March 2000. This identifies four key objectives:

- to make work pay and provide secure income;
- to make pensions safe and pension systems sustainable;
- to promote social inclusion;
- to ensure high quality and sustainability of health care.

All four of these refer to supporting independent living.

### **2.3 UK Status and Development**

The following is a very brief overview of economic, health and social policy developments relating to independent living in later life in the UK. Much of the UN and European Commission sentiment is echoed in the UK development. It will become clear too that a lot of the research-based evidence for supporting independent living in later life has been crystallized in actual policy implementation.

The United Kingdom has an ageing population and in excess of 7 million people with some form of disability (Department of Health 2000), and Government policies for older and disabled people aim to:

- promote health and independence
- provide person-centred services to meet individual needs
- help people live in the community
- support carers
- modernise and integrate services
- deliver value for money.

Information and Communication Technology (ICT) is seen as one of the means to promote the independence of older people and help them live in their own homes. In 1998, the NHS Executive (NHS Executive 1998) recognized that *telecare technology will be used to provide reliable but unobtrusive supervision of vulnerable people who want to sustain an independent life in their own home*. The report of the Royal Commission on Long-Term Care underlined disability equipment and housing adaptation and the contribution of assistive technology as important factors (Royal Commission on Long-Term Care 1999), and in 2000 the Audit Commission reported that almost 1 million people needed equipment to help them live independently in the community, pointing out that this could be the gateway to their independence, dignity and self-esteem (Audit Commission 2000).

Modern day Community Care for older people has its roots in National Assistance Act of 1948 which laid out the central role of the local authority residential home without provision, however, to develop home care services (and related services) to prevent older people from moving into residential care, although the 1946 National Health Service Act did enable local authorities to develop home care services for the aged. Enabling older people to stay in their

own homes for as long as possible is not a late 20<sup>th</sup> century aim. Indeed, the Ministry of Health Annual Report of 1953 spoke of *the universal recognition of the urgency of the task of enabling old people to go on living in their own homes as long as possible*, and the 1954 Annual Report added the importance of delaying the admission to residential care for as long as possible. Only six years later, the 1960 Ministry Annual Report was even more categorical in its views, stating that *the general objective of both health and welfare services, working in cooperation, is to maintain the elderly in the community and to accept admission to hospital or residential care as the right course only where an old person himself accepts the necessity for this and when he has reached a point where the community services are no longer sufficient* (Ministry of Health 1954, 1955, 1961). However, not until 1971 with the creation of social services departments did local authorities receive legal powers to develop services, which might support older people and enable them to remain in their own homes. The White Paper on community care in 1989 still emphasizes the need for older people to stay at home for as long as possible and the need for flexible alternatives to residential and nursing home care. It is clearly stated in the objectives of the White Paper that the right amount of care and support should be provided to help people achieve maximum possible independence, including the provision of support to informal carers. The objectives required flexible and sensitive services; a range of options; services should foster independence; and services should concentrate on those with the greatest needs (Department of Health 1989).

Both the health and social care domains have witnessed a host of policy developments over recent years, particularly with regard to older people. The emphasis on the idea of independent living, incorporating the notion of self-reliance, has formed the basis for much recent health and social care policy.

The NHS and Community Care Act 1990 sought to alter the provision of care for older persons. The various aims were to encourage the development of community care provision and to reduce care home placements and to shift the impetus away from central government and over to local government.

The emphasis on choice and autonomy in terms of selecting the care home was underscored. However, key problems with long-term care in terms of funding remained, and a Royal Commission on Long-Term Care was established. A key recommendation from this Commission was that care should be paid for through taxation as opposed to by the residents themselves. The 2001 Labour Party Manifesto, *Ambitions for Britain*, identified pensioners' needs for simple accessible services promoting independent living, and the Department for Work and Pensions is committed through its Public Service Agreement (PSA) targets to promoting independence in retirement and to modernising welfare delivery to improve service accessibility, among other things.

The National Service Framework for Older People (NSF) is the main policy instrument through which commitment is made to modernising health and social care services (Department of Health 2001). The goals of the NSF for older people include: "promoting independence and person-centred care, improving the quality and consistency of services, expanding service capacity and the reform of long-term care".

In July 2000, the Government announced in the NHS Plan the development of services for older people to minimise admissions to hospitals and/or residential care, support early hospital discharge, and reduce bed-blocking (Department of Health 2000).

Better Care, Higher Standards is the charter for long term care. Implemented from 2000, it is a joint measure from the Department of Health (DoH) and the Department of the Environment, Transport and the Regions (DETR), acting to inform those in receipt of care of the standards they can expect.

The ***Supporting People Programme*** (DETR 2001a) will provide housing-related support for vulnerable people from April 2003, but includes areas such as information services and access to wider web services (DETR 2001). The programme offers vulnerable people the opportunity to improve their quality of life by *providing positive services, which enable them to have greater independence and control in making choices within their lives*. It will act as partnership of Local Government, the NHS, the National probation Service, service users and support agencies. It is seen as a key factor and driving force in combating social exclusion.

*“Effective housing, allied to the right care, support and wider services, such as good transport and community safety, can be the springboard that enables older people to remain involved and live their lives to the full”*. (DETR 2001)

A joint publication from the Department of the Environment, Transport and the Regions and the Department of Health (2001a) states that *housing, care and support policies need to focus on enabling older people to live as part of the community in their own homes, in comfort and safety and in the best possible health, for as long as they wish to do so*.

The ***Interministerial Group (IMG)*** for older people was established in 1998 with the aim of presenting an overview of policy as it effects older people.

*Care Direct* – implemented as a pilot scheme in 2001 - was a Department of Health led service linked to *NHS Direct* but run locally by local authorities in partnership with other government and non-government organisations. **The Government made a commitment in the 2001 election Manifesto to provide a Third Age Service for pensioners with the following statement – ‘Pensioners.....need simple accessible services that treat them with dignity and promote independence. We will build on Care direct to provide a better integration of health, housing, benefits and social care for older people.**

## **2.4 UK Organisational Policy Statements**

Both Age Concern and Help the Aged were asked to contribute to the research team’s work by submitting any of their relevant policy work on issues relating to independent living in later life. Once again, the statements in this section are the responsibility solely of the organisations concerned and reflect in no way the views of the research team.

Although there is an organisational opposition to charging older people for personal care services and low level housing support services, there is also the view that if charges for these services are to remain then they should take due account of the individual’s circumstances and disposable income after services have been paid for. There are organisational concerns about the

effects of charging for Supporting People services on the incomes of older people not entitled to Supporting People services or those on partial housing benefit as far as charges may make it difficult for them to stay in sheltered housing schemes. It is felt that older people should be entitled to free Supporting People services as the support element of service charges in sheltered housing are generally low, thus enabling older people to access the support services needed to live independently at home and at the same time ensuring that incomes are protected and remain stable. Any charging system introduced should be transparent, affordable and fair.

As some older people become frail and in need of high levels of personal care, staying at home may become unrealistic. Very sheltered or extra care sheltered housing is a popular model of care in such instances and seen as an alternative to moving into residential care. It seeks to maintain a certain degree of independence despite the frailty of the older person. The care elements of services provided in extra care sheltered housing schemes is regulated by the homecare provision of the Care Standards Act 2000 (CSA), and the Supporting People programme will monitor the basic housing related support services. As far as policy initiatives to promote user safety in care service provision are concerned there are organisational concerns that care homes required to register under the CSA may seek to avoid this by redefining themselves as extra care sheltered housing. It is feared that the CSA could limit the range of housing options available to frail older people.

Naturally, the financial security of older people is of major organisational concern. There is an overwhelming climate of concern and uncertainty with regard to the future of pensions in the country, and many people are losing confidence in current schemes, which can have a detrimental effect on people's propensity to save for old age. There are significant and worrying gaps in knowledge about pensions and savings, and it is felt that more research and modelling are required. Budget standards would provide a benchmark of the total level of income needed to secure a comfortable requirement. Adequate incomes in retirement should be secured by a combination of state and private income. Risks must be minimised and protection must be an optimum. Employers should be informed and supported to encourage them to provide occupational pensions.

Improving the quality of life of older people – which is one distinct strand for prevention – requires a broad policy front, ranging from addressing poverty and housing to transport, and to better diagnosis and treatment of the common ailments associated with old age. The second prevention strand relates to preventing the need for more intensive services, and this itself requires easier and earlier access to information, the promotion of all aspects of healthy ageing, and substantial investment in social care and community health services.

### 3. CONCEPTS OF INDEPENDENCE

This section will relate to the key factors identified as being central for independent living in later life. It will draw together the main themes from the literature reviewed employing the expert review based methodology described in Chapter 2 covering control/empowerment, living arrangements/housing, economic security, social/familial networks and health and social care. Twenty Key Studies have been identified and for each section key studies are presented. The literature on Independent Living per se is extremely limited, the literature on the five broad factors identified above is considerable. Given the timing and scope of the DWP review requirements, it was agreed that the review would only cover that literature which **explicitly or directly referred to independence, dependence or independent living**.

#### 3.1 The interpretation of the concept of independent living

It is important to note that the concepts of *independent living* and *independency* have attracted limited explicit coverage in the current research literature. However much research has been undertaken which addresses concepts directly related to independence and independent living. Indeed a striking feature of much of the literature reviewed is that the concept of *independence in later life* is often freely and widely used but never explicitly defined by the authors. It is as if this concept is readily and widely understood. However, the definition of *independence* is as difficult and diverse as that of *quality of life*, where sectoral and cultural factors can determine the definition (Gössweiner et al 2001). From this literature we can conclude that independence is a complex and subjective concept, yet one which is generally regarded by both policy makers and many researchers as having a positive impact on the quality of life of older people.

In a discussion paper prepared in 2000 for the National Strategy for an Ageing Australia (COTA 2000), it is stressed that the concepts of independence and (economic) self-provision should be viewed separately and that *a broad definition of independence should incorporate the idea of choice in life-style and the maximisation of opportunities for social and economic participation*. Furthermore, the paper puts forward that independence in older ages will be most effectively enhanced by the achievement of healthy ageing by virtue of:

- sound economic, social and environmental conditions including adequate and equitable income distribution through paid employment and social security provisions;
- well developed communities, high levels of accessibility and appropriate living situations;
- a range of health and community service programmes to support healthy ageing.

The research literature suggests that we must address concepts of independent living at two broad levels:

1. The subjective views of older people themselves
2. The structural constraints laid down by society.

### ***The subjective views of older people themselves***

The concept of independence is rated highly by older people in as much as it encompasses the subconcepts of individuality, self-esteem, control and empowerment, and more importantly perhaps *the absence of dependence* (Leeson 2001; Phillipson et al 2001). Furthermore, future generations of older people, while recognizing the potentiality of dependence in old age, expect to be able to live independently in old age (Tanner 2001; Leeson 2001), and even among the present generations of older people there is for the majority a feeling of independence and satisfaction (Leeson 1999; Hansen & Platz 1995, 1996). For the most frail older people in residential care, however, the (professional) concept of independence and self-determination seems misplaced (Christophersen 1999).

Older people are rarely heard and if heard then muted in many academic analyses of policies. Thus health, financial and social service provision developed for older people is often determined by the perceptions of policy makers and service providers and not by older people themselves. (Wilson 1991, 1997). Consulting older people as consumers and purchasers of services is a relatively new phenomenon in the policy making world. Otherwise, surveys have been the traditional avenue by which the views and aspirations of older people were channelled into policy making. On the other hand, it can be debated whether or not the elucidation of independence, barriers to independence and independence enhancing initiatives are suitable for user involvement, at least as far as expecting older people to predict future situations are concerned. It is perhaps easier to analyse the move into dependence in a retrospective sense with older people and their families more able to describe what went wrong and what was missing.

However, older people are clearly able to discuss and define their quality of life. This is clearly illustrated by Farquhar (1995) who used in-depth unstructured interviews on a sample of some 200 older people aged 65 years and over. Farquhar's study highlighted characteristics of the older person themselves which influenced their perceptions of quality of life. In this study, for example, *age* was significant, with older people more likely to describe the quality of their life negatively; *location* with older people in semi-rural areas more likely to describe the quality of their life positively; and *health*, with good health seen as important to high quality life. Leeson's (2001) large national structured questionnaire study of old and young people in Denmark also addresses this question of perception of quality of life. In this study strong *family ties*, *social contacts* and *maintaining activities* are viewed by the older respondents as valuable components of high quality life. Both this study and the community based semi-structured interviews by Phillipson et al (2001), exploring older people and their communities in the UK, reveal that *independence* is regarded by the respondents as an important aspect of their quality of life. As Leeson (2001) explores, it would seem that this may be a case of fearing what they see as dependence on other people's help and support in old age, and a fear of not being able to access the help and support when they need it.

Furthermore, there is evidence that older people themselves increasingly expect to be able to live independently in later life (Tanner 2001), but such *self-expectation* does not always correspond to *general expectation*. However, as we shall later explore, this focus on independence as a positive quality of life enhancing factor may be misleading in some situations. Perhaps this is seen most clearly in the comparison often made between *living at home* and *living in a home*, the former being regarded as more independent than the latter.

### ***The constraints laid down by society***

Over the last twenty years the concept of *structural dependency* has been used by various researchers as a framework for understanding the societal constraints faced in later life. It thus provides a means also of understanding the concept of independence in later life. In the early 1980's Townsend (1981) argued that a number of socio-economic constructs such as retirement, pensions and residential care defined a dependent old age. Walker (1982) took up the idea and concluded among other things that the growth and development of social services is based on restricted assumptions about the nature of dependency. The resultant structured dependency paradigm argued that older people have no alternative but to come to terms with social welfare outcomes and be grateful for the care and support they receive (Townsend 1981).

Walker (1982) provides a very comprehensive review of the different aspects of dependency and old age, covering life-cycle dependency, physical and mental dependency, political dependency, financial dependency, structural dependency, and the social construction of dependency in old age, and he points out that *the challenge confronting policy analysts is to examine the institutional processes which create and sustain dependency...(to) better understand and so counteract the development of dependency in old age.*

While structured dependency is now viewed in a more critical light, in part due to the recognition of individual action which arose from the literature of the 1990's addressing individuation, citizenship, and empowerment (Biggs, 1998), it highlighted the key role that institutions play in providing the context for individual ageing.

## **3.2 Aspects of independent living**

In this section, we shall consider aspects of independent living arising from the research in relation to the factors outlined above as being key to promoting and determining independent living in later life. Although an attempt is made to structure the findings by factor, there is a great deal of interrelationship between the individual factors.

### ***Control / Empowerment***

While few studies explicitly address the idea of control and empowerment in relation to independent living per se, control/empowerment is clearly central to older people's perception of independence.

Full and active citizenship as endorsed by the United Nations and the European Commission brings with it both rights and responsibilities, and the importance of this citizenship seems to be a cornerstone in the move to ensuring independence in old age (Carell et al 1997; Biggs, 1998), so much so that legislation creating elected seniors' councils has been introduced in Scandinavia (Mathiesen 1997; Daatland 1997). Indeed, there is general importance placed on the political participation of older people across Europe (Carell et al 1997). This was recently highlighted by the conference held by the German Federal Ministry of Family Affairs, Senior Citizens, Women and Youth in 1997

This of course relates to control and empowerment at the collective level, but there are equally important concepts at the individual level where it is vital for individuals to feel that they are able to exercise choice (control) in their daily life (Hayden et al 1999). Laukannen et al (2001),

for example, point out that the most crucial factor with regard to autonomy is to retain one's functional capacity and to cope with everyday routines for as long as possible despite illness. Critical assessment of the research literature revealed that the most pertinent manner in which this factor emerged in direct relationship to independent living was in the lack of user involvement in the development of services for older people.

### **Key Studies 1**

A key example of this can be seen through analysis of the implementation of the 1990 NHS and Community Care Act. This brought with it marketisation characterised by the purchaser/provider distinction, self-provision and quality assurance. With marketisation comes the expectation that older people behave as consumers. The quality assurance systems introduced to enhance standards of care may in fact inhibit quite dramatically empowerment. It is suggested that the language of quality assurance and the professionalism of the 1990s has strengthened ageism in social care (Oldman & Quilgars 1999). Many of the quality assurance initiatives are aimed more at the purchaser and regulator than the consumer (the older person). In the research of Oldman & Quilgars (1999), older people receiving home care and older people in care homes used the language of the consumer and were not simply passive recipients of care. There was little difference in this matter between self-payers and publicly-funded residents. Entitlement to be critical was universal. Oldman & Quilgars (1999) argue that providers are paying no more than lip service to the principles of empowerment and independence. Their research reveals that neither care home residents nor older people in their own homes felt particularly involved in care delivery processes such as assessment, care planning and review.

Although some older people do see themselves as critical consumers, their power is limited in fact and the idea of empowerment rather meaningless. Neither home care recipients nor care home residents felt particularly involved in care delivery processes such as assessment, care planning, and review (Oldman & Quilgars 1999). The evidence of Hardy et al (1999) confirms that there is still a significant divergence when it comes to what the consumer regards as ideal and the practicalities they meet.

### ***Living arrangements/Housing***

Living arrangements and housing is one of the few areas of research to explicitly address independence. A central theme here however is that independence is clearly related to the idea of enabling older people to remain in their own homes for as long as possible. From this arises the contrast between *living in a home* and *living at home*.

The choice of present home as the most desired in old age may also reflect a lack of knowledge of suitable alternative living arrangements, or it may even reflect a denial/fear of old age and dependency, which is portrayed by the living at home / living in a home dichotomy. This dichotomy has apparently been so strong that original assertions that institutions never could resemble home (Willcocks et al 1987) are now moderated by the fact that they now try to provide more domestic environments. The wariness older people express with regard to moving into residential care settings may, however, still be justified in light of the fact that such settings continue to threaten the sense of self (Peace et al 1997).

It should be noted, however, that much of the discussion about living arrangements in later life is based on rather limited empirical investigations addressing the preferences of older people and future older people themselves (see Leeson, 2001 and Daatland, 1997 as exceptions). As Wilson (1991, 1997) points out, surveys often have as their point of departure pre-conceived ideas about the attitudes, behaviour and aspirations of older people, relating more therefore to the assumptive world of policy makers and service providers than to that of older people.

### **Residential care**

Residential care in Britain has typically been seen as a provision of last resort (Means & Smith 1994) never able to take on the characteristics of home (Willcocks et al 1987), with residential settings representing a profound threat to the sense of self (Peace et al 1997). Indeed the early research on living in *residential care* focused almost exclusively on its depersonalising effects (Booth 1985; Hughes & Wilkin 1987; Willcocks et al 1987). This dependency fear is clearly stated by older people currently living in their own homes and is also reflected by researchers' views in the research on residential care (Counsel & Care 1992) where there is a fear and loathing of residential care (Peace et al 1997). A study of home care clients, for example, saw a move into residential care as losing one's individuality, sitting around doing nothing, being ordered around by others (Oldman & Quilgars 1999).

However it should also be noted that Oldman & Quilgars (1999) also reveal how misleading this view of residential settings may be in as much as their research shows that for some older people a move into a care home is seen as a move to increased independence, releasing them from the burden of being cared for by relatives. In addition, their research reveals that for care home residents, the poverty of their lives (loneliness, depression and a hard life) before the move into the care home is expressed as a common theme.

A difference between home and residential care is also found in the behaviour of care providers in the two settings (Twigg 1997), with care providers behaving in a more constrained fashion in older people's own homes. Twigg (1997) notes that the behaviour of care deliverers toward older people depends on the care setting, arguing that it is more difficult for an older person's own home to come under the control of professionals because the norms of home as a private, autonomous place are shared by the providers themselves. This is not true of a care home setting where there are no similar shared norms that contribute to the independence and self-esteem of older people – on the contrary. It seems sensible therefore that moves be made to identify and promote residential care settings as being the home of the individual older person, something which Bland (1999) sees as possible and something which Danish legislation has attempted to promote by giving residential care home residents the same basic tenancy and consumer rights as older people living in their own homes. As Christophersen (1999) has pointed out in the Danish context, legislation alone is not enough. There must be a change of attitude among professionals. As Jensen (2001) suggests, involving family members more actively in the business of the home may contribute positively to changing the attitudes of professionals.

However, in the work of Oldman & Quilgars (1999) at least 50 per cent of the home care clients living in ordinary housing reported that care assistants did not respect them. Community services which are *highly routinised with set times for home helps* and where *social work intervention may be focused around narrowly defined and practically-orientated activities* leave little scope for independence and control (Baldwin et al 1993). The stereotypical view of the

older person in residential care as a victim of institutionalisation and the idea that life in residential care *exists separately from and beyond the normal constraints of community life* need to be challenged (Reed & Payton 1996).

Research reveals that once in residence the majority of care home residents viewed their new living arrangements quite positively (Allen et al 1992; Oldman & Quilgars 1999). The move was actually seen as an *accommodation change* rather than a *move into care*. Indeed, for some it was a step towards increased independence meaning they were no longer dependent on relatives and thereby able to have a better relationship with them, a view also found among residents in retirement communities (Kingston et al 2001).

Kingston et al (2001) find that older people living in such communities maintain their physical and mental health compared with older people in the local neighbourhood. Analysis revealed that the main factors leading to maintained health status were support from peers, safety and security, and *autonomy with inclusion*. The authors point to a *feel good factor* in the retirement community environment, which had been chosen because of the security offered and because it removed the burden of family care for the family and for the older person.

With a slightly different emphasis, Dalley (1993) sees the tension between carer and dependent relative as an argument for residential living arrangements. The role of relatives after a move into a care home should not be forgotten, however, as they remain the link with the outside community, making the home part of a community rather than a closed sphere (Reed & Payton 1996).

An illustration of this from Europe can be found in Denmark, for example, with its well-developed welfare state providing comprehensive and extensive care and support for older people. Quantitative studies confirm (Platz 1981, 1987, 1989, 1990; Hansen & Platz 1995, 1996) that older people are independent and satisfied. However, these quantitative studies on their own admission were not able to include the most frail (and dependent) older people in their universe. Even in-depth qualitative studies can fall foul of this same selection process (Oldman & Quilgars 1999). Refreshingly, therefore, Christophersen (1999) adopted an anthropological approach in order to determine the quality of life of the most frail older people in residential care settings. However this study found that the (professional) concepts of independence and self-determination did not always harmonize with promoting the optimum quality of life for these residents.

In a qualitative study among older people receiving home help services prior to the transition to home care in a London Borough, Godfrey (1995) found that there was a clear desire by many to struggle with personal care tasks rather than receive help because being able to carry out these tasks – painful and time-consuming though it may be – was regarded as enabling them to remain autonomous. On the other hand, they were happy to receive help with housework, as this did not threaten their feeling of independence in any way. These results would seem to support the suggestion that preventive services should be supportive in helping older people compensate for frailty while maintaining autonomy.

## **Key Studies 2**

A Dutch study considers explicitly the factors, which push frail older people out of independence and into a residential home (Steverink 2001).. Steverink's work has three stated aims: to consider the use of residential homes; to illustrate more clearly the concept of need in relation to living in a residential home; to devise a theoretical model which determines why frail older people differ in their inclination to live in a residential home. Steverink draws on data from the Groningen Longitudinal Aging Study (GLAS) (Ormel et al 1992). Selection from the base-line sample of GLAS gave 607 frail older people living in their own homes (with a more able spouse) with an average age of 75.7 years, 75 per cent female, 45 per cent widowed and 45 per cent married. Interviews were carried out in the homes of the respondents. The analysis focuses on frail older people's *orientation towards living in an old age home*. Comfort and affection are revealed as decisive. Income is found to have a significant effect on orientation, but does not seem to work to counter loss of comfort. Both formal and informal care were found to affect orientation significantly, but they did not counteract loss of comfort. While informal care does not apparently reduce comfort's effect on orientation, formal care actually seems to enhance the effect. The author explains this by summarising that older people in receipt of formal care will have little comfort and little affection and therefore over and above receiving formal care these older people will also be inclined to consider living in a home. The conclusion then is that formal care will not delay a move into a home – quite the contrary. One of the weaknesses pointed out by Steverink is the fact that the study is cross-sectional, and there is thus a need for more longitudinal research. The most conclusive policy recommendation from the paper is that formal care - capable only of providing comfort - should support informal carers in their task of providing the affection that formal care cannot give.

#### **Key Studies 3 and 4**

Two pieces of research based on qualitative data sets by Quilgars et al (1997) and Oldman et al (1998) respectively comprise 101 in-depth interviews with 48 clients of home care (Quilgars et al 1997) and 53 residents in 12 different care homes (Oldman et al 1998) throughout the country. Almost all of the older were aged 80 years and over and they were in poor health. Most of them had limited mobility and difficulty performing basic daily tasks such as dressing, bathing, shopping. The fluid nature of the boundaries between housing and care are evident in these studies, brought together in Oldman & Quilgars (1999). Those resident in care homes had en-suite facilities furnished with their own furniture. Each flat had its own letterbox. Some of the home care clients were living in sheltered housing but are defined in the study as living at home – they are tenants with housing rights, the schemes were not extra care, and they lived in self-contained flats. Home care clients were negative about moving into a home but described their lives at home as quite bleak, in many ways supporting a contention that institutionalisation actually describes the lives of many older people living in the community (Baldwin et al 1993) who feel bored, lonely and trapped in their homes.

#### **Key Studies 5 and 6**

The ability to treat older people living in residential care settings as autonomous adults and to manage any associated risk is the focus of work by Bland (1999). She suggests that the approach adopted in the private home she studies is based on the owners' experience of providing a residential service and managing hospitality in hotels, something which preserved and promoted the values of independence, choice, privacy and dignity for residents. This was in striking contrast to the social care approach in local authority homes. Central to this approach was the fact that the right of residents to independence and autonomy was not contested. Any risks were managed with the help of technical aids instead of placing restrictions of the freedom of movement and activity of the residents. In addition, it was the case that staff and residents shared the same understanding of the normal social conventions, though as Christophersen (1999) points out staff often are subject to practical constraints that prevent them from acting in the way they would prefer to act. In the private home, residents were not regarded and treated as frail, vulnerable older people in need of care and protection. On the contrary, residents were seen as being experts on their own needs. The owners had no professional role that could be undermined by allowing the residents to exercise choice and make decisions that affected their own daily living. In the service they provided, personal care was but one element rather than being the dominating factor. The fact that privacy is also seen as a core value in social care homes is undermined by the need to minimize risk. This leads to the denial of privacy. Bland feels that there is doubt as to whether residential care homes should be run like hospitals, hotels or domestic residences. This doubt means the staff and residents do not share the same understanding. In Bland's view, the attitudes of social care staff have not been changed by codes of practice and quality of care guidelines – at the root of the demise is the ideology of care, which prevents or at least makes change difficult.

We also need to address the area of sheltered housing. Older people in sheltered housing do not necessarily share the view that they are living *at home* in contrast to *in a home*, the key factor being that they are no longer living in the home-setting they had experienced previously. However, this feeling may be transitional and result from the timing of the research. As Means (1997) has pointed out, older people will re-establish feelings of self-identity following a housing move, given time.

### **Key Studies 7**

An overview of the newer forms of enhanced sheltered housing examines the claims that they can reduce reliance on or even replace residential care (Oldman 2000). This work is based on semi-structured telephone interviews with the main providers of very sheltered housing, and other key players, along with case study evaluation of innovative housing and care in York. Tenants in enhanced sheltered housing schemes generally had higher disposable incomes and more choice and control, and relatives were involved to a greater degree. The schemes were not generally cheaper than residential care. Although the enhanced sheltered housing schemes aimed to create an active community and to deliver services in accordance with the concept of independent living, these aims could be hampered by admission criteria focusing on dependency levels. The study revealed tension between the desire to develop an active (independence enhancing) community and to operate as an alternative to residential care, with residents in three of the schemes involved not wanting to live in a place where everyone was frail. In comparison with residential care, the schemes provided more space, flexible care and a vibrant community,

and interviews with tenants suggested that they saw the benefits as improved quality of life and a greater feeling of both physical and psychological security. Indeed, the majority felt able after the move into the scheme to do things, which they had been unable to do for some time.

### **Home**

It is striking how central *the home* is to the concept of independence both in policy terms and in the statements of older people. Since the 1960s the meaning of home to older people has also been the subject of extensive research (Townsend 1963; Willcocks et al 1987; Higgins 1989; Sixsmith 1986, 1990; Saunders 1990; Gurney and Means 1993; Dupuis & Thorns 1996; Means 1997). The emphasis in this research has been to emphasize a romantic picture of life at home in old age. However this literature also reveals how responses vary according to gender, class, ethnicity, country and age, as well as how the perception of home and its meaning change and evolve over time. Saunders (1990) also stresses that identification with the home as a source of independence and self-expression is greatest for those who own. In contrast those who rent identify more with the neighbourhood or local community.

In Means (1997) for example, all respondents stressed a desire to remain as independent as possible with many stressing the importance of the home as a place where they could express their individuality as well as their desire to retain control over their own lives. Among future generations of older people, the present home is seen as the most favoured accommodation in old age, even if it should become difficult to cope alone (Leeson 2000).

### **Key Studies 8**

By drawing on research on 39 older people from 31 households in four localities in 1996 (a large Midlands city, a city in the South West, two London boroughs and a market town in the North West), Means (1997) illustrates the importance of home as a place of privacy and self-identity as well as the richness and variety of the lives of the older people concerned both inside and outside their homes. Respondents were aged between 60 and 98 years. Twenty of the households were owner-occupiers and 11 were rented while 10 were in sheltered housing schemes (6 rented and 4 private schemes). Home was seen as a place of privacy and refuge, a place to do what you want to do when you want to do it. There was a strong preference to *stay put* among both owners and tenants, both because it was home but also because it was close to good neighbours and friends. The majority of those who had moved into sheltered accommodation had settled and regarded their new accommodation as their home, although the positive views were tempered by criticism of the size of the accommodation. Especially illness or death (of spouse) can change one's attitudes to home. Dissatisfaction with one's present house centred on concern for repairs and an inability to look after the house and garden. Almost all of those interviewed by Means stressed their desire to be as independent as possible, and many linked independence and maintenance of independence to being active outside the home. This was however dependent on access to transport which in turn meant that the low frequency of bus services, poor access standards on buses and the expense of keeping cars were major

concerns. There was an equally strong desire to avoid becoming dependent upon family, friends, or the social services.

### *Economic Security*

Much of the literature on economic security is concerned with the consequences of population ageing on retirement income provision from a macro perspective, relating to pension schemes and the pension mix. However, such studies and overviews can provide some interesting information of relevance to the independent living in later life discussion (Davis 2000; OIA Working Papers 2002). In the UK, for example, approximately 70 per cent of old age benefits is financed by basic pay-as-you-go schemes compared with the EU average of 83 per cent, with a further 18 per cent financed by supplementary, compulsory pay-as-you-go schemes compared with the EU average of 7 per cent (Davis 2000). One of the messages in the pension debate seems to be that if policies are not adjusted then social security pension systems will lead to increases in the intergenerational redistribution with both employers and employees contributing more for the same pension with the burden effectively being transferred to future generations. Policy options being discussed are many and varied and with a varying likelihood of success: increasing retirement age, decreasing benefit levels, increasing controlled immigration. In addition the Government issued a green paper exploring way to encourage people to save for their retirement. (DWP, 2002).

The Eurobarometer survey (Walker 1993) is notably the most comprehensive quantitative survey of the general attitudes of older people across Europe and as such provides a wealth of information, which outlines the central concerns of older people with regard to financial matters. This includes information on attitudes to financial independence through items relating to the adequacy of pension provision, what constitutes financial security, the minimum level of resources that should be provided by the State, provision of concessions for basic daily living items. It does seem, however, that people have great difficulty assessing the scope of their financial security in old age (Leeson 2001), fears of not being able to make ends meet prior to retirement being allayed for the majority, although this may again be a case of older people adapting to the new situation.

Very few studies have explicitly addressed both independent living and economic security. Dependency can be interpreted in a financial sense meaning complete or partial reliance on financial support from the state. Low income has long been viewed as restricting an individual's ability to take part in various activities (Haggstrom 1964). Indeed, a recent Scottish survey (Scottish Executive 1999) revealed that less affluent older people were more likely than others to experience activity limitations and isolation, and most of those identified as socially isolated were not using social services.

From the perspective of the individual financial support is stated as a key issue quite clearly in some instances. For example, in an Irish study of the views of older people receiving informal care, increased financial support for themselves was stated by over half of the sample as being of importance, with 64 per cent stating this to be important for their carer (McCann and Evans 2002).

The uptake of State benefits may rely not only on the knowledge of the different types of help available but also on the best way to access these services (Kempson et al 2002). This lack of knowledge about services and how to access them is a major reason for needs remaining unmet with regard to support at home in general (Scottish Executive 1999).

#### Key Studies 9

In a study by Mack et al (1997) which attempted to use alternative assessment of independence to the more usual activities of daily living indicators, financial considerations were mentioned as requirements for remaining (independent) in the community, but what the participants meant by this was quite different from the meaning in typical instrumental activities of daily living tools (IADLs). While the IADL financial aspect relates to *being able to continue to manage their finances competently*, which is thus a mental capability in the IADL tools, participants focused not surprisingly on having adequate finances to sustain their current living arrangements. Economic problems are seen thus as more of a threat than not being able to manage one's money.

#### Key Studies 10

Much of the recent debate has highlighted the difficulties people face in understanding their pension schemes and the provision these will give. A very recent national general population study (CIPD 2003) confirms that large numbers of people do not understand their pension schemes, although understanding and awareness seems to be greater among those closer to retirement. Even so, 20 per cent of those aged 50 and over had little or no understanding of their pension schemes. There was concern among a third about the future performance of pension schemes. Over 90 per cent of public sector employees trust their employer with their pension schemes. There was a strikingly low level of awareness of the cost of financial comfort on retirement. Of the total sample of 599 persons, only 26 per cent stated that they had worked out how much they would need to retire comfortably – even among those closest to retirement (aged 50 years and over), only 46 per cent stated this. And this is of course no guarantee that they have calculated correctly. Only 51 per cent of respondents were members of their current employer's pension scheme (40 per cent of the under 25s and working rising to 58 per cent of the over 50s and working), the largest proportion of 66 per cent being among public sector employees. Topping up with additional voluntary contributions was not widespread with only 48 per cent of the over 50s and working stating that they had done this compared with 24 per cent of the under 25s and working and 30 per cent of the 25-50s and working. A third of respondents do not feel that a good pension scheme is as important to them as a good salary. This proportion, however, declines with increasing age from 43 per cent of the under 25s and working to 21 per cent of the over 50s and working. Interestingly, only 45 per cent of respondents were aware of the Government's public consultation regarding pensions.

## Key Studies 11

Whetstone (2002), for example, considers pensioner poverty in an ethnographic study of 50 people aged 70 years and over living in a deprived Central London area. It is a harsh picture of how those older people dependent on a state pension and income support – 25 per cent of the pensioner population in the country – are forced to make difficult choices to survive. Furthermore it has been estimated that in 2000/2001 between 450,000 and 670,000 pensioners may have been entitled to MIG (MIG (now replaced by Pension Credit) but not claiming it <http://www.dwp.gov.uk/asd/irb.html>. As Whetstone points out little is known of life as an older person on a low income with studies of this nature rarely focusing on older people at all. She concludes that the majority of problems faced by her study group are the result of inadequate public policies. They are let down by poor service and long waiting times in the national health service which then leads to their social exclusion, and because of their housing location in deprived areas, their fear of crime also prevents them from taking part in activities outside the home. Being forced to live on an income below the minimum income level, they make harsh choices to survive, very often spending less on (good) food. A total lack of financial independence leads to lack of choice and an existence apart from others. The vicious circle of their poverty trap is striking.

### *Social and Familial Networks*

The changing structure of families in ageing societies does not mean that the role of families in supporting older people is decreasing in importance (Harper 2003). The family does in fact seem to be more important today for middle aged and older generations than was the case 10-15 years ago (Leeson 2001). In contemporary society, there are, however, many competing demands on and roles for family members – one of which is care-giving, for children, spouses, parents, parents-in-law, and perhaps even other family members or friends.

Literature in this area has tended to focus on care giver burden rather than on promoting independence per se. However the limited work that does address this considers such networks as either networks of care or networks of support.

In considering the multifaceted role of social and familial networks in caring for and supporting older people, the life course perspective seems particularly relevant (Cook et al 1997) as the cultural context of care-giving changes over time, as the family structure and inter-familial relationships change over time. Comprehensive European studies of the family care of older people (Le Bris 1993; Leeson & Hoffmann 1993;) reveal the complex aspects of this phenomenon both for the caregiver and the cared-for and the cultural settings. The size and density of a social or familial network are not per se positively linked to perceived support and independence. Large, closely-knit families can be sources of intrusiveness, bad advice and conflict as well as support. Indeed, there may even be an inverse relationship between the size of the network and receipt of support. Pickett et al (1993) indicated that potential supportive resources sometimes may have an adverse effect.

The importance of networks for independence versus dependence seems to be well documented, although it could be argued that there are doubts as to the direction of effect. In this respect, it is interesting to consider environmental effects on networks, and in the Netherlands, Thomese & van Tilburg (2000) have considered the effects of neighbourhood characteristics on the size and composition of neighbouring networks for older people living independently. Based on an analysis of networks of almost 4000 respondents, they found that the composition of core networks (persons within 10 minutes travel distance) depended on the degree of urbanisation in as much as older people in highly urbanised areas had smaller neighbouring networks but larger core networks within one hour's travel. Neighbouring networks made up on average 60 per cent of these core networks, and 78 per cent of the core network could be reached within one hour's travel. Most of the neighbouring networks (61 per cent) comprised non-kin. Urban networks differ in composition but not necessarily size from rural networks. Stability of the population is an important determinant of network size, regardless of the degree of urbanisation. The relative size of the neighbouring network was not affected by the proportion of age peers nor by the proportion of lower-income households in the neighbourhood, although the authors do themselves question the robustness of these results. Individual income affected older people's susceptibility to environmental influence on their neighbouring networks. For example, better off older people in sparsely populated neighbourhoods had relatively smaller neighbouring networks than was the case for other rural residents – these were pension migrants.

Taking a different angle on the literature, it is clear that independence in later life is often linked into active, healthy ageing. Older people are generally extremely active as far as leisure time pursuits are concerned and a desire for social contact is reported as one of the main reasons for taking part in various activities (Audun-Olsen & Mølholm 1988). The benefits of taking part in such activities thus involve both those arising from developing and sustaining a social network, as well as healthy activity, and the psychological benefits from structuring one's time after retirement (Young & Schuller 1991). A recent US study emphasises this message. Results from a 13-year prospective study of almost 3000 Americans aged 65 years and over reveal that social and productive activities that involve little or no enhancement of fitness lower the risk of all causes of mortality as much as fitness activities do (Martin 1997). The message is clear is that *having a reasonable quantity and quality of social relationships is essential for mental and physical health* (Martin 1997). Furthermore, the effect on mortality proves to be greatest among the least physically active. This leads to speculation that the beneficial effects of fitness activity may derive as much from the incidental social and purposeful activity involved as from the effect on cardio-pulmonary fitness. However, once again as in many other areas of the review, such large scale quantitative research can only provide some of the evidence needed to measure the beneficial effects of active ageing and help towards an understanding of how to promote well being in old age.

In a Dutch study (Thomese & van Tilburg 2000), the situation of so-called pension migrants in relation to neighbouring networks is noted. These migrants had moved to rural areas without compensating for the loss of their former (urban) neighbours and friends, and as such they had relatively smaller neighbouring networks than others in the rural areas. In addition, this study revealed that the degree of urbanisation had a strong effect on the relative size of neighbouring networks for older people with low incomes. This is of interest in relation to independence as older people are regarded as being rather dependent on neighbouring networks – they are

assumed to be dependent on their physical environment and the way this environment promotes or inhibits the maintenance of their relationships with others.

Paying regular home visits to old people aged 75 and over in their own homes has proved to be beneficial for their quality of life (Hendriksen et al 1984) as well as acting as an effective preventative tool as far as inhibiting the transition of older people into dependence is concerned. Such visits contribute significantly to reduce acute hospital care. And those results along with others (Rademacker Jensen 1997) imply strongly that primary health care is very important for those older people receiving help and support from familial or social networks. Family carers are often coping with older people's (severe) medical conditions and the older person's feelings of loneliness and depression, which then put strain on the carer (Thorslund et al 1991; Herlitz and Dahlberg 1999). The professional carers need to take on the role of educator and co-worker in relation to the family carer both to inform about nursing care and to ease the strain of being a carer (Nolan et al 1996).

The key message arising from this literature is that independence should not be confused with isolation and nor does it equate with no receipt of support from formal or informal sources. Indeed, supportive services may be enabling (Clarke et al 1995) but they may also be disabling (Leeson 1992), just as large familial networks can be sources of intrusiveness (Lefley 1997) and have an adverse effect (Pickett et al 1993).

### **Key Studies 12**

Twigg and Atkin (1995) consider the factors mediating the relationship between carers and service provision in relation to the service given to carers. The authors identify a number of significant factors: the attitude of the carer and the views of the person being cared for and the views of other family members, family relationships and the *moral status* of the person being cared for, and gender, age, class and race. The singularity and the interaction of the factors is underlined. The research is based on qualitative interviews with 90 carers (identified from random surveys of the population) and 66 service providers (identified through the carer interviews) in two areas. In their study, Twigg and Atkin find that assertive carers who push for help end up getting help, something confirmed by the service providers in the study, who explained that they did not generally seek out cases and that help *was to some degree determined by factors extraneous to 'need'*. Clearly, the person being cared for also plays a role when services are negotiated, although for some this is difficult because of their frailty. This is important as service providers respond to the person being cared for and his/her needs and actively encourage their right to play a central role in negotiations. However, despite this acknowledgment, service providers *varied in the degree to which they were willing to compromise that right in the interest of the carer*. It was felt that the gender of the carer should not influence the provision of support, but there was some evidence in the study that some forms of support were given more often to male carers than to female carers, something found in earlier studies too (Arber et al 1988). Traditionally, it seems that domestic help to older people was more often denied if there were a female family member nearby. In the study of Twigg and Atkin, service managers stated that this was no longer practice, but *there was evidence of its survival at the level of front line personnel*

### **Key Studies 13**

In considering the frequency of care received by a sample of 448 older people aged 75 years and over living in their own homes in a medium sized Swedish city, Hellstrom and Hallberg (2001) discover that even within such a supposedly well developed state-subsidised system of care provision, care is mainly provided by the older person's family or larger social network. Up to 80 per cent of those interviewed (dependent on age) were dependent on help, and only 53 per cent of the sample received help from formal sources. In fact, home nursing care staff had very little contact with the sample and the home help services only had contact with about half of the sample. They conclude that contributions from next of kin far exceed those from formal carers, indicating that a family based approach is needed in care of older people. The fact that only half of the sample were in contact with formal care services is not necessarily an indication that formal care staff are aware of those in need and those able to cope for themselves. Olivius et al (1996) showed that neither those in charge of home help services nor those in charge of home nursing care had sufficient knowledge about the older people in their areas of responsibility.

#### **Key Studies 14**

In Thomese & van Tilburg 2000 the effect of urbanization and other environmental characteristics on older people's neighboring networks and thus independence is elucidated in this large Dutch study. They found that the composition of core networks depended on the degree of urbanisation in as much as older people in highly urbanised areas had smaller neighbouring networks but larger core networks within one hour's travel. Urban networks appear to differ in composition but not necessarily size from rural networks. Stability of the population turns out to be an important determinant of network size, regardless of the degree of urbanisation. The relative size of the neighbouring network was not affected by the proportion of age peers nor by the proportion of lower-income households in the neighbourhood, although the authors do themselves question the robustness of these particular results. Individual income affected older people's susceptibility to environmental influence on their neighbouring networks. For example, better off older people in sparsely populated neighbourhoods had relatively smaller neighbouring networks than was the case for other rural residents – these were pension migrants.

#### ***Health and Social Care***

Independence is most often measured in terms of dependence, in terms of functional disability rather than ability, basing assessments on activities of daily living (ADL) and instrumental activities of daily living (IADL). In fact, IADLs like using the telephone, controlling medication and preparing meals, are more relevant to older people's ability to remain in the community. Regardless of the indicators employed to measure (in)dependence, it is clear that threats to independence are much more complex. ADL/IADL indicators are weak on a number of accounts: they lack a strong theoretical basis and their development has had little input from older people themselves ((Mack et al 1997). A large number of factors, which are considered to be important for remaining in the community by older people themselves, are different from and

more extensive than the content of ADL and IADL assessment tools. As Mack et al (1997) point out a sense of identity is necessary to be able to remain in the community. Participants in this study mentioned *inner strength*, *get-up-and-go*, and *not wanting to depend on others* as important characteristics and that without these they would be at serious risk. Mack et al (1997) claim that this concept in particular underlines the inadequacy of ADL and IADL functioning in relation to independence. Autonomy was also frequently cited by the older people in the study as being the reason for wanting to remain in the community.

Exploring the most important aspect of subjective independence, Leeson (1999) and Audun-Olsen (2000) show that good health is clearly seen as determining independence. Qualitative studies can contribute significantly to an understanding of well being, as with Clark et al (1998). What is often central to self-esteem has nothing to do with the services that can be provided. Self-rated health has frequently been used as a substitute for clinical assessment and as a basis for use of health services (Fylkesnes 1993).

Kingston et al (2001) find that older people living in age-specific housing or retirement communities maintain their physical and mental health compared with older people in the local neighbourhood. Analysis revealed that the main factors leading to maintained health status were support from peers, safety and security, and *autonomy with inclusion*. The authors point to a *feel good factor* in the retirement community environment, which had been chosen because of the security offered and because it removed the burden of family care for the family and for the older person. There may of course be a selection process at work, with residents in age-specific housing simply being more advantaged than other older people which allows them to make a conscious choice to move into such housing.

The role of formal carers and their attitudes towards older people in different care settings need addressing if the contended ageism of care is to be removed and replaced by what in essence is a more humanitarian view of older people in need of support and care. Christophersen (1999) claims on the basis of her anthropological studies of life in residential care settings that the majority of formal carers do indeed have these humanitarian views, highlighting independence and self-determination of even the most frail older people as important aspects of their quality of life. However, she points out that rigid structures in the homes and time constraints especially mean that there is little room for such views to be put into the practicalities of caring.

Advice services placed in primary care seem to have the potential to reduce health and social inequality, but more research is needed to elucidate the take up of such services and the health and social status of those taking up such services (Abbott and Hobby 2003). In a qualitative study among older people receiving home help services prior to the transition to home care in a London Borough, Godfrey (1995) found that there was a clear desire by many to struggle with personal care tasks rather than receive help because being able to carry out these tasks – painful and time-consuming though it may be – was regarded as enabling them to remain autonomous. On the other hand, they were happy to receive help with housework, as this did not threaten their feeling of independence in any way. These results would seem to support the suggestion that preventive services should be supportive in helping older people compensate for frailty while maintaining autonomy and independence.

Recent work by Elkan et al (2001) evaluates the effectiveness of programmes of home visits to older people - including frail older people living at home - offering health promotion and

preventive care measures with a view to determining whether these measures reduce mortality levels, admissions to hospitals and institutions, and improve both functional and health status. They found significantly reduced levels of mortality, even among frail older people, and a significant reduction in admissions to long-term care.

The list of areas suggested by the research for action is - if not endless - then most certainly comprehensive. Means (1997) argues that local authorities must take the lead in promoting the independence of older people, developing *a broad vision of community care, which covers issues such as transport, leisure and household maintenance*. His research though showing the positive attitude of older people to the services they receive does also reveal that they have concerns about the rigidity of the service system. One of his own main concerns arising from his research is the plight of older people who are not regarded as belonging to a high need category, and he calls for a wider vision of community care that would also respond to low level needs as meeting these would enable older people to maintain their independence in the home of their choice. Older people with relatively high incomes find themselves able to buy into the independent sector to meet these needs, but this was not an option for older people who were dependent on state benefits. The danger, as he points out, is that those unable to buy into support from the independent sector will be forced to wait until a crisis casts them into the high need category and the spiral into dependence.

### **Key Studies 15**

Health and social care of older people links into familial and social networks and their role in promoting independence, even in cases of (severe) illness, as reported in the Swedish study by Hellstrom and Hallberg (2001). In this study families are handling medical problems - in some cases severe conditions. Almost all the sample of older people reported at least one – and in most cases several – disease(s) and a number of complaints, all of which are instrumental in making them dependent on help and reducing their quality of life. Demographic aspects did not contribute to a low quality of life. This was further exacerbated by feelings of loneliness and depression. Between approximately 4 and 10 per cent of the sample could not be on their own at all, and between 18 and 31 per cent could only be on their own for relatively short periods of time. A third of the sample reported low quality of life.

### **Key Studies 16 and 17**

A recent Dutch pilot study of the Longitudinal Aging Study Amsterdam examined the effects of physical activity and the possible mediating role of perceived physical self-efficacy on self-rated health among 55-89 year olds in the Netherlands, based on a random sample of 60 males and 60 females (Parkatti et al 1998). Physical activity proved to be a significant predictor of self-rated health, and perceived physical self-efficacy explained self-rated health status even after controlling for age, gender, living arrangements, and chronic diseases.

A recent Finnish study with a study population of almost 6000 had as its aim to elucidate the functional capacity of older people cared for in different health and welfare care settings (Laukkanen et al 2001).

The study revealed that women receiving home nursing had the best functional capacity while women in long-term care at health centre hospitals had the poorest, which may be because men receive help from their wife enabling them to live at home even in poor condition. The authors conclude that policies assigning older people to different care settings appear to be sound and sensible, as the main defining criterion is level of functional capacity rather than age. However, they do also point out that the decision to move into institutional care is not simply a health related one but also depends on the availability of institutional places (beds) and on admission criteria, acknowledging that the ready availability of places/beds in itself increases the numbers going into long-term care. In other words, the number of places/beds is not directly related to the size of the need in the older population for institutional places nor on the perception of dependence.

### **Key Studies 18**

A key study addressing how older people viewed, accessed and experienced support services was undertaken by the Scottish Executive (1999). This study investigated needs and service provision from the perspective of people aged 75 years and over living in their own homes. The study sample comprised a total of 1022 people from Glasgow and Edinburgh. A postal survey was carried out and among those indicating they needed support in-depth interviews were carried with 79 people. From the postal survey it was found that just over half of the sample felt they were limited by illness and disability with almost a third stating they were limited in mobility or ability to perform everyday tasks. Almost one third of the people surveyed felt that they needed help with one or more aspects of daily living. Just less than 30 per cent had little social contact, and less affluent people were more likely than others to experience limitations and isolation. A number of factors such as housing situation, income and social contact influenced whether people felt they needed support. The location of facilities was important in determining how much support was needed. Users of services were more likely to be living alone and in rented housing, and most people identified as socially isolated were not using social services. The in-depth interviews showed that both users and non-users of services experienced unmet needs – being a client of the social work department did not always lead to people receiving the range of services they themselves felt they needed. Advice was not given on alternative sources of support if a service was declined. Perceived needs were not met mostly because of a lack of suitable services, lack of knowledge about services or individual choice not to use the services. Even when a service was clearly needed, some people chose not to make use of them – reasons given for this were feelings of discomfort, embarrassment and anxiety, all of which seem to underline the perception of receipt of services in a negative light. Forty per cent of those identified as most in need of support said they did not use home or day care services.

The Scottish study also reveals the key role of the GP in monitoring the well being of older people and making referrals to other services. Very few of the older people interviewed regarded the social work department as a source of information or advice. Knowledge of the workings of the department and individual rights was extremely limited.

Independence in arranging their own support services was valued highly and the attendance allowance was the means of achieving this for most. Access to this allowance depended on help from others rather than from the benefits agency. The benefits agency was replaced by

Jobcentre Plus and the Pension Service in April 2001. There has not been a followup survey to see if this policy change altered these results.

### **Key Studies 19**

Abbott and Hobby (2003) have investigated who actually takes up welfare benefits advice services in primary care. The commissioning of welfare benefits advice services in primary healthcare settings is seen as part of local strategies to reduce health inequalities, but little is known about the contribution to health of such services. In their longitudinal study, Abbott and Hobby have considered 345 people aged 54 years on average, likely to be unemployed or retired. Three quarters reported a physical disability or long-term illness and they were generally speaking in poorer health than the population norms. Over 85 per cent of them were advised to apply for welfare benefits, most commonly Disability Living Allowance. Access to the service had been facilitated by their general practitioner (one third of the sample), by a family member or friend (one fifth of the sample), from other members of the primary health care team (almost 12 per cent), or from the advice service itself (almost 12 per cent). Almost all of the sample (90 per cent) had contacted the advice service seeking welfare benefits advice and almost a third had used similar services elsewhere. Only one fifth had been in receipt of no benefits prior to advice. Services situated in primary care seemed to attract older clients. The authors claim that those working in primary care who are sceptical about placing such services in primary care (Abbott and Hobby 1999) might be persuaded to change their minds if they were aware of the fact that over half of those likely to use the service were eligible for Disability Benefit, so that advice services could help reduce health and social inequality.

### **Key Studies 20**

Stoddart et al (2002) elucidate the factors determining the use of home care services (both private and statutory) by older people living in their own homes. Their postal questionnaire survey was carried out among a stratified random sample of 2000 persons aged 65 years and over registered with general practices in a British city. The response rate was 79 per cent after 47 persons had been removed from the original sample because they had either moved from the area or died. Non-response was greater among the oldest of the sample and among females, so the results may also be biased in that the non-responders may be in poorer health, more isolated. The authors themselves advise caution on generalising their results to the broader national population since the communities sampled were more affluent and with smaller proportions of ethnic minorities than the national averages. Of the surveyed sample, 14.4 per cent used statutory home care services and 10.7 per cent used private home care services. Findings were quite similar for both private and statutory services. Age, car ownership and widowerhood/widowhood affected the use of statutory services for both sexes. Males who were single, divorced or separated had a higher incidence of use of statutory services. Females with longer full-time education used statutory services less, whereas both males and females with longer full-time education used private services to a greater extent. For both forms of service, service use increased with poorer self-reported health status. It was also found that

weaker/smaller social networks were associated with greater use of statutory services, but these effects disappeared once demographic factors were controlled. The authors also point out that the use of both forms of service was greater than had been previously reported, perhaps because of the ageing of the population and the tendency to maintain older people in their own homes for as long as possible.

## 4. PROMOTION OF INDEPENDENT LIVING IN LATER LIFE

Chapter 4 will now turn to consider how an understanding of these individual factors – control/empowerment; living arrangements/housing; economic security; social and familial networks; and health and social care – behind the concept of independence may assist in the policy promotion of independent living in later life.

### 4.1 Supporting independent living – the role of government, local authorities, the voluntary sector, formal and informal carers.

It is tempting to consider separately the role of the various players who together determine, or at least shape, the degree of independence in older people's lives. The failure to acknowledge and act on the fact that the actions of all players are interrelated – be it government, local authorities, the private sector, the voluntary sector, social or familial networks – is probably one of the major contributory factors developing and retaining dependency in old age. Indeed, those writing within the structured dependency paradigm of the 1980s argued that growth and development of social services in the UK was based on restricted assumptions about the nature of dependency. They further suggested that older people have no alternative but to come to terms with social welfare outcomes and be grateful for the care and support they receive (Townsend, 1981; Walker, 1982). If we take a more older-persons centred approach we can start to achieve the joined-up thinking and working now promoted by the government. Leeson (2001b) argues that methods should be devised which robustly elucidate and then integrate older peoples levels of satisfaction with services, into the subsequent development of *user-orientated services*.

The most comprehensive source of evidence of need for practical and low-level support services for older people in their own homes emerges from the General Household Survey: Follow-up Survey of the Health of People aged 65 and over (Goddard, 1998)<sup>1</sup>. This revealed strong gender and age effects with older women being most in need. However across the age spectrum, local authority services provide only a small proportion of the help required.

Among the over 65s only between one third and a one half of those in need received this help from a local authority provided service.

- 35% of those requiring help with getting out and about receive this from the local authority
- 47% needing help with dressing receive this from the local authority
- 40% needing help with bathing receive this from the local authority
- 34% of those unable to cook a main meal on their own received at least one of local authority home help, meals on wheels, lunch club help, or day centre help

Among the over 85's

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<sup>1</sup> A sample of individuals who were aged 65 and over when interviewed on the GHS and who gave permission to recall were interviewed. The set sample is about 1400 individuals in about 1000 households. This is a sub-sample of eligible GHS respondents - all those aged 85 and over at the time of the follow-up survey are included and about half of the rest. The sub-sampling has been done so that in households where two elderly people were interviewed on the GHS, both will again be interviewed. Tracing and flagging respondents on the NHSCR was undertaken to avoid contacting respondents who had died and to enable a comparison of those who had died with those who were still alive. Interviews took place in March and April 1997 for this survey. The original GHS 1994 interviews were conducted April 1994 to March 1995.

- Almost half of women aged 85 years and over are unable to get out of doors and walk down the road alone, and 31 per cent are unable to get up and down stairs or steps alone.
- However only 20 per cent of women aged 85 years and over received local authority home help services compared with 31 per cent receiving private home help.

Key to the provision of providing joined up user-orientated services to facilitate independent living in later life is a greater understanding of older people's perspectives; the interface between formal and informal care; and structural constraints.

#### 4.1.1 The perspective of older people themselves.

In assessing the perspective of older people themselves. We need to address

- how older people themselves view support services
- how they access them
- how they experience accessing them.

The following factors emerge from the literature. The **[numbers]** refer to the sub-sections in Chapter Three.

**a. The physical location of facilities** and services must always be considered in relation to the distribution and needs of the local older population. **[3.2.5]**

#### **b. Access to services**

2.1 Access to services was through the following in rank order **[3.2.5]**

- GPs
- Family or friends
- Primary Health Care Team
- Advice Services

2.2 The GP plays a key role in monitoring the well being of older people and making referrals to other services. **[3.2.5]**

2.3 Social work departments are not viewed as either a source of information nor of advice or advice. **[3.2.5]**

2.3 Independence in arranging their own support services was valued highly by many older people. **[3.2.1]**

2.4 Financially the Attendance Allowance was an important means of achieving independent arrangements. **[3.2.3]**

2.5 Knowledge of individual rights was extremely limited. **[3.2.1]**

2.6 Advice services placed in primary care seem to have the potential to reduce health and social inequality, but more research is needed to elucidate the take up of such services and the health and social status of those taking up such services. **[3.2.5]**

### **c. Users of services**

3.1 Users of services were more likely to be living alone and in rented housing, though most people identified as socially isolated were not using social services. [3.2.2/5]

3.2 Being a client of the social work department did not always lead to people receiving the range of services they themselves felt they needed. [3.2.5]

3.3 Perceived needs were not met mostly because of a lack of suitable services, lack of knowledge about services or individual choice not to use the services. [3.2.5]

3.4 Even when a service was clearly needed, some people chose not to make use of them. There is thus evidence that up to nearly half in most need of support may not be using home or day care services. [3.2.5]

3.5 Older people in receipt of formal care provision may lack both comfort and affection in the context of these services. This may paradoxically encourage them to consider living in a residential home [3.2.5]

### **d. Impact of marketisation on satisfaction**

With the impasse of marketisation into the provision of health and social care and support services, service providers have become keenly aware of documenting the satisfaction of consumers. However, measuring the degree of satisfaction of older people with the services they receive is fraught with problems, which may lead to misleading and incorrect conclusions that older people are indeed extremely satisfied with the services as they seem to be with much of their situation. Older people who are dependent on home care services are not inclined to criticize the service, and evaluation methods rarely take into account the whole set of factors in an older person's life that affect their ability to determine their satisfaction with the services received. [3.2.2/5]

#### **4.1.2 The interface between the formal and informal caring profession.**

A second key area of importance is the interface between the formal and informal caring profession. The following factors emerge from the literature:

##### **a. Ageism**

1.1 There is some evidence of ageism among the attitudes of formal carers [3.2.1]

1.2 The role of formal carers and their attitudes towards older people in different care settings need addressing if a more humanitarian view of older people in need of support and care is to be taken. [3.2.1/5]

1.3 The majority of formal carers do indeed have these humanitarian views, highlighting independence and self-determination of even the most frail older people as important aspects of their quality of life. [3.2.1]

##### **b. The care setting**

2.1 The care setting is crucial in policy measures towards regulating the behaviour of formal care deliverers toward older people. [3.2.2]

2.2 It is more difficult for an older person's own home to come under the control of professional care givers. [3.2.2]

2.2 The norms of home as a private, autonomous place are shared by both the older person and the professional caregivers. [3.2.2]

Rigid structures in the homes and time constraints especially mean that there is little room for such views to be put into the practicalities of caring. [3.2.2]

This is not true of a care home setting where there are no similar shared norms that contribute to the independence and self-esteem of older people. [3.2.2]

### c. Informal or family care

3.1 Family carers are often coping with older people's (severe) medical conditions and the older person's feelings of loneliness and depression, which then put strain on the carer.

3.2 Involving family members more actively in the business of the home may contribute positively to changing the attitudes of professionals. [3.2.4]

3.3 The factors mediating the relationship between carers and service provision in relation to the service given to carers include: [3.2.4]

- the attitudes of both the carer and care recipient
- the views of other family members
- gender, age, class, race and financial status.

3.4 Gender and age in particular appear to informally determine the degree and type of formal support given to carers[3.2.4]

- Some forms of support are given more often to male carers than to female carers.
- The reactions of service providers to younger and older carers respectively were quite different. It was acceptable to help younger carers develop a life of their own (pursue careers, marry etc.).
- Males carers who were single, divorced or separated had a higher incidence of use of statutory services.

3.5 The professional carers need to take on the role of educator and co-worker in relation to the family carer both to inform about nursing care and to ease the strain of being a carer. [3.2.4/5]

### 4.1.3 Structural constraints

The third contributory factor is the structural constraints: institutions (government, local authority, voluntary) and environment. The following factors emerge from the literature:

3.1 **Social work departments**, which are not proactive, place the responsibility for maintaining contact with vulnerable isolated older people on others, most notably voluntary groups. [3.2.5]

3.2 Long-term funding for **voluntary and community-based** activities needs to be secured. [3.2.5]

3.3 A stronger social services presence in **primary care settings** could improve monitoring of older people's welfare and a wider access to the type of support services that would help them maintain their independence. [3.2.5]

3.4 A more proactive role of the Benefits Agency ( **which is now disbanded with the formation of now jobcentre plus and the pensions service**) would secure a greater take-up of benefits and this would release health and social care staff from the responsibility of assisting older people with claims. **The Pension Service local service and local authorities are now exploring ways of working together as joint-teams in assessing older people's needs** [3.2.5]

3.6 Programmes of **home visits** to older people giving health promotion and preventive care measures have proved to be beneficial for quality of life as well as acting as an effective preventative tool as far as inhibiting the transition of older people into dependence is concerned. [3.2.5]

3.5 The promotion of better **information** and closer contact between policy makers, practitioners, users and potential users of service is necessary if service users are to see themselves as empowered consumers rather than passive recipients of services. [3.2.1/5

## 4.2 Independence versus dependence

The following key points emerged from the literature

4.2.1 Independence versus dependence is easily seen as *living at home* versus *living in a home*. However, the research shows that there is no such clear-cut distinction in terms of independence. Furthermore, the views of older people themselves in relation to a move into a home did not always coincide with the prevailing professional and societal view of such a move being *a move into care*.

4.2.2 It is clear too from the research that there is an inherent danger of generalisation in a struggle to quantify independence. Measures such as ADLs and IADLs although importantly measuring functional abilities do not necessarily pick up on the person-specific aspects of what they consider to be decisive in terms of maintaining independence.

4.2.3 Most of the reviewed literature focuses on the promotion of independence, that is to say the factors which enable older people to remain independent. However, as Oldman & Quilgars (1999) point out a move into a care home can be and is often seen as a conscious change of living arrangements, which actually enhances independence.

4.2.4 There seems to be no stable illustration in the literature towards the end of the 20th century of what actually determines older people's need for long-term care in homes. In fact, it would indeed seem that older people with varying degrees of need along the complete scale of need are to be found both in the community and in homes, underlining again that the individuality of need – and therefore independence – is central to this discussion (Newman et al 1990). Indeed as earlier stated, older people in receipt of formal care provision may lack both comfort and affection in the context of these services. This may paradoxically encourage them to consider living in a residential home

**4.2.5 While it does seem that impairment is a necessary prerequisite for the transition to dependence, other factors such as financial status, age, gender, whether or not one lives alone, and the availability of informal care have a more complex effect. The actual factorial interrelationship is however unclear.**

### 4.3 Conclusion

Although it is possible to identify factors – as we have done in this review – that clearly influence the independence of the individual, the weighting of each factor in the collective assessment of independence varies from person to person. Nor does the impact of one necessarily lead to a transition into independence. Older people and their families develop compensatory strategies, which enable overall independence despite the fact that independence has been threatened on one or more fronts.

It does seem decidedly clear from the chapters of this review on the definitions of independence, the factors affecting independence, and ways of supporting independence that there is a great degree of overlap, that it is extremely difficult and perhaps even misleading to categorize independence in a rigid fashion.

Likewise when we consider independence versus dependence. An individual may have certain dependence characteristics, which are counteracted in one way or another (by home adaptations, targeted service provision, family care support), thereby allowing the individual to maintain a large degree of independence in the setting he/she chooses. It does seem too that promoting even modest degrees of independence can be vitally important for the individual in maintaining their self-respect and dignity (Christophersen 1999).

An interesting aspect of independence versus dependence comes to light when considering the merits of age-specific housing or retirement communities. On the one hand, such housing for older people can be seen as combining positive features of residential care and of community living. On the other hand, they can be seen as schemes, which increase the dependency of older people and thereby the demands for service and support.

**It seems clear that user-centred services and a user-centred appraisal of needs, which includes the broader familial and social network of older people, would support older people's perceptions and experiences of independence. Equally important is a norm shift among all players which would see services supporting independence rather than underlining dependence.**

## 5. THE EUROPEAN EXPERIENCE – A TWO NATION CASE STUDY

Across Europe, the concept of independent living in later life can be regarded quite differently from country to country at the national level, depending on the history of and the prevailing culture of care, which in turn will often be reflected in the welfare models in place. Some of these differences come to light in the literature reviewed in the preceding chapters of the review, but some of the more interesting European experience is presented in this chapter on the basis not of research or literature but interview or reports back from contacts. Two case studies are presented from Denmark and Italy respectively. These two countries are deemed by the OIA team as representing very different welfare regimes with different social and familial network structures, all of which affect the approach to promoting independent living in later life.

In the following, two in-depth case studies are presented. The two countries have been chosen as representatives of quite different state welfare/family structures. In Denmark, two senior policy consultants from DaneAge were interviewed (Olav Felbo and Margrethe Kahler) along with Director of Policy Analysis at DaneAge, Jens Hoejgaard, and in Italy, Dr. Raffaello Belli from the National Council for Research in Florence was interviewed. The views given in the case studies are thus the views of these persons and not of the OIA research team. The interviewees were identified as independent experts in the field of independent living, able to give an overview of the situation and development as well as an independent appraisal where appropriate of the effect of initiatives<sup>2</sup>.

### 5.1 The Danish experience

As pointed out by Olav Felbo and Margrethe Kahler, the philosophy driving the development of present ageing policies in Denmark has two components:

1. older people will experience a greater degree of satisfaction if they are given more **choice** and more **control** with regard to the services they receive from the public sector;
2. there should be more **transparency** with regard to prioritisation decisions and how funds are allocated (a development which began in the 1990s).

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<sup>2</sup> As a third example – but separate from the more in-depth case studies – experience in Greece is outlined in that it provides a further illustration of differences in welfare and network structures. The contacts identified for the three countries have broad and lengthy experience of working in the fields of ageing and/or independent living, both nationally and at the European level. The information on Greece is provided by the named Greek contact, Dr. Elisabeth Mestheneos, both in talks and in forwarded material. In Greece, the fact that so few older people live in any form of institutional care (simply because this is not provided), then ostensibly older people are living independently in as much as they are living in the community. However, there has been extensive family support (Le Bris 1993), which *undermines* this idea of independence in a lot of cases. Across the country, there are approximately 400 so-called KAPIs (similar to day-centres) which provide support for social and health related activities in the community, in the course of the last three years, 150 home help services – many attached to the local KAPIs – have been developed on the initiative of the government by local authorities and with EU funding to support mainly isolated older people. There is a significant number of migrant workers working as domestic care-support workers for older people, and government allows them (and their employers) to pay a lower level of insurance contribution. This is to encourage them to register as legal immigrants and workers, and indirectly is perhaps a policy that acknowledges their role in the care of older people in the community. Greece has no sheltered housing schemes established by local authorities or by the public sector, but older people have to a limited extent established semi-sheltered units, meaning basically that they live next door to their children.

As far as **choice** and **control** are concerned, a milestone was the introduction in July 2002 of flexible home help (including personal care assistance). Flexibility encompasses timing and content within a framework determined by the local authority. The interviewees explained, however, that there is a general fear that especially frail older people may be subject to manipulation by personnel, and therefore the local authority is still responsible for ensuring that vital tasks are carried out. In other words, in the final instance, the local authority can decide that the wishes of an older person are contrary to *what is best for them*, contrary to professional judgement of need. The interviewees find it strange that the law does not commit the local authority to reveal to the older person receiving home help just how much home help (in terms of time) they have been given. They feel this will make it difficult obviously for the older person to plan actively the use of the allotted home-help-time. It appears that most opposition to revealing the time allotted has come from the Local Government Association, whose main argument is that this would focus attention on *time* rather than *tasks*. Representatives of older people's organisations fear that local government opposition is because they want to be in control of *time*.

Felbo pointed out that being able to exercise **choice** demands that the consumer (older person) is aware of the right and the possibilities. The onus of informing the consumer is on the personnel, and he felt that this may be problematic as personnel organisations are sceptical. He explained that their main worry is that it will prove difficult with consumer choice and flexibility for them to plan the working day, never knowing beforehand the wishes of the consumer and therefore the workload of individual personnel. There is also a professional fear that consumer choice and service flexibility will undermine service quality. Felbo explained that in the 1980s, there was a strong move to improve the service qualifications of personnel as this was believed to improve service quality. Consumer choice and flexibility means that service quality has no professional basis, but it is simply the consumer's subjective view. Given this scepticism, he felt that one could justifiably worry that the incentive to inform the consumer about **choice** will be affected.

**Choice** entails the consumer being in a position to choose who should perform the home-help tasks they have been allotted by the local authority. This is a major development, ending 30 years of local authority home-help monopoly. Local authorities must develop service quality guidelines for themselves AND for private providers, but the local authority retains responsibility for control of the service provided. The capability of the local authority to control private providers has been questioned, as has the capability of private providers to secure qualified staff.

The law stipulates that the consumer (older person) **shall** make a conscious choice – it is not simply a question of being able to choose. All persons allotted help and care services will receive information about the providers available (including the local authority). There may be different providers for different services, and there will most certainly be significant regional and local differences in the **degree of real choice**, simply because sparsely populated areas will be less attractive for private providers.

**Choice** demands that the consumer is capable of acting as a consumer. This is not simply a question of having the information to make a choice. It is also a physical and psychological question of being able to make a choice.

As far as *transparency* is concerned, the Danish interviewees felt that perhaps the most significant element of the legislation is that once the local authority decides one is eligible for help and service, one has legal rights. Receipt of the service becomes a right. And with the legal right comes the right to compensation in the event of failure. The consumer is to be made aware of these rights and of the service to be provided, thereby enabling the consumer to evaluate the service. The consumer will have one person employed by the local authority to whom eventual complaints are to be made, and the whole complaints process has been improved in line with the developments. In determining the service to be provided, new procedures have been introduced. First and foremost, the wishes and capabilities of the consumer are recorded. The consumer's living arrangements, state of health, social and familial networks etc. are evaluated – the evaluation is holistic. The philosophy underpinning this approach is that the consumer and the local authority agree on the terms and conditions and prerequisites underlying the determination of the amount, kind and level of service to be provided.

Kahler explained that *housing* policies for older people in Denmark continue to develop the philosophy of being able to stay in the home of one's choice for as long as possible, which was introduced in the 1970s. Today, there are approximately 86,000 units of specialised public sector housing for older people, and of these 20,000 are units in residential nursing homes. It is widely acknowledged by all players, that the pursuit of this policy was too dramatic in the 1990s. It should be noted that all homes are run by local authorities. From 1987, residential nursing homes could no longer be developed and in general terms the policy aimed to differentiate between *the home* on the one hand and *service* on the other hand. Older people living in an institutional setting were to be seen as no different from older people living in their own homes, and many elements of institutionalised settings were (forcibly) removed. Residents were given tenancy agreements for their own independent home (in what had been an institution) and should pay for individual service elements rather than a complete institutional package. Existing nursing home rooms/flats were improved and enlarged, the result being that the number of such places available declined and many local authorities were no longer able to provide for the most frail residents. The waiting list for admission to a residential nursing home (which can no longer be called that) is approximately 5000 persons. Since 2001, all institutional settings are required to establish *Family Councils* comprising representatives of residents, family members, management and the local authority.

The move now is towards *modern nursing homes*, independent living arrangements in an environment of intensive service and care facilities. For the more independent elderly, local authorities are encouraging *collective living arrangements* which offer independence and peer support (backed up by local authority support).

*Flexibility* has also been a keyword in this area, as Felbo and Kahler underlined. Moves began in the early 1990s to allow older people to move into residential nursing homes outside their own municipality, allowing them to move closer to family. Initially, there were restrictions – both authorities had to agree that the individual needed to move into a home, one had to have particular familial or religious grounds for such a move. The familial restriction was removed in 2002. Approximately 1000-2000 older people make use of this flexibility.

In terms of *financial security* and independent living, Hoejgaard described how several features of the Danish development are noteworthy. In view of the fact that older people in homes were given tenancy agreements and moved from a service package to paying for service elements,

residents moved from *pocket money* (their pension was withheld to cover costs and they were paid a symbolic amount of pocket money per month) to *pension*. For older people living in their own homes, the financial security system has remained the same for many years. Housing allowances are designed to enable people to remain in the home they have, and there are mechanisms whereby home-owners can receive similar financial support (in the form of loans against the security of their home). However, there are no financial support mechanisms enabling older home owners to adapt their homes to independent living in later life.

The present government introduced an *elderly check*. Approximately 1/6 of the country's 700,000 old age pensioners would be eligible for the check (up to 500 pounds sterling before tax) in 2003. There will be negotiations to introduce this as a permanent subsidy.

There are a number of financial allowances, which could be regarded as promoting independence – adult education allowance for older people (this has been reduced) – but many of the previous wealth of individual allowances have recently been reduced or removed completely, and there are significant local differences as local authorities allocate such allowances on the basis of individual evaluation.

More information about DaneAge: [www.aeldresagen.dk](http://www.aeldresagen.dk).

## 5.2 The Italian experience

*“Independent living is not a matter of life style,  
it is a matter of basic freedom”*

*Dr. Raffaello Belli*

In Italy, independent living is a concept related primarily to disabled persons, but it is beginning to be considered in relation to older people. However, there is quite substantial experience from the disabled field, and considering this underlines the parallels with the situation of older people. For example, that one of the stated *main obstacles to independent living in Italy is that many people with disabilities are segregated in institutions or in their families...because of the lack of personal support, lack of mobility possibilities, lack of technical aids...many of these people with disabilities are forced into to be confined in institutions, or if they have the possibility to stay at home, they have very few opportunities to live a socially integrated life* (Belli 1991). The similarities with the situation of many older people risking dependency are striking. Belli goes on to state that many of those running institutions along with the parents of disabled people are one of the largest barriers to independence. To the list of barriers is also added the inefficiency of public administration. For example, it can take up to five years for an application for a state allowance to be processed, and an appeal against a decision can take up to 10 years. There is a minimum 12 months wait for a wheelchair. Against this backdrop of barriers, there are, Belli points out, a number of points facilitating independent living. Examples are monthly allowances. Government has legislated and provided (modest) funds to enhance accessibility in the public domain, but this has not moved into the private (housing) domain.

At the National Council for Research in Florence, Dr. Raffaello Belli is responsible for disability rights and independent living and in that capacity has developed an impressive international information website ([www.idg.cnr.it/guide](http://www.idg.cnr.it/guide)). Dr. Belli is also a member of the

board of the European Network on Independent Living. It is interesting to note that the term *independent living* seems to have been adopted by the ageing sector from the disability field, but at the same time there seems to be little interaction between the two sectors. It would doubtless be a useful exercise in furthering an understanding of independent living and the sort of policy initiatives that could be envisaged if independent living in the disability field were investigated. In Italy, older people would in relation to independent living be covered by the legislation relating to people with disabilities.

In Italy, the 21 regions have autonomous rights to legislate on independent living. There is national legislation and provision in the Italian constitution relating to independent living (basic freedoms), and despite their autonomy, the regions are required not to legislate in contradiction with national legislation. However, that does not oblige them to follow national legislation automatically, and this lead along with their autonomy does lead to significant regional differences with regard to conditions for independent living.

Tuscany was the first region to adopt its own legislation on independent living, coming into effect prior to the National Law adopted in 1992. Indeed, the Tuscan legislation inspired the national initiative. One of the flaws of the national legislation, according to Dr. Belli, is the fact that personal assistance is only granted to people with severe disabilities. This forces disabled people to apply for recognition as severely disabled simply to be able to receive personal assistance, the result then being that the Italian statistics on people with severe disabilities are inflated.

Much of what can – and more particularly what cannot – be done in terms of independent living depends on funding, and regional authorities often state lack of funding as the reason for not being able to live up to the aims of the national legislation.

Italy is regarded as very advanced as far as the integration of disabled students in ordinary schools is concerned (although this is primarily due to the fact that there are no special schools). This integration, it is felt, is extremely important in relation to independent living later in life. The feeling is that becoming disabled at age 20-30 years, for example, means one actually knows what independent living entails (i.e. making your own decisions about certain daily tasks, bathing, for example) and one can make an attempt to continue living independently. If, however, one is born disabled, integration is the only way one will discover the elements of independent living, putting one thereby in a position to aspire to this. Comparing this with the situation of older people, dependency comes out of independence – one is aware of the erosion of one's independence.

In 1998, a law was passed in Italy guaranteeing the right to independent living – and older people are included in this legislation. Thus, independent living has become a right for every citizen in Italy. The system of regional autonomy, however, does mean that regional parliaments also have to adopt this law before citizens actually can claim their right to independence. Having said that, there have been successful court cases where persons have claimed their constitutional rights to independent living in relation to the regional authorities.

## 6. POLICY AND RESEARCH RECOMMENDATIONS

It does seem decidedly clear from the chapters of this review on the definitions of independence, the factors affecting independence, and ways of supporting independence that there is a great degree of overlap, that it is extremely difficult and perhaps even misleading to categorize independence in a rigid fashion. An individual may have certain dependence characteristics, which are counteracted in one way or another (by home adaptations, targeted service provision, family care support), thereby allowing the individual to maintain a large degree of independence in the setting he/she chooses. However, promoting even modest degrees of independence can be vitally important for the individual in maintaining their self-respect and dignity (Christophersen 1999). An overriding policy consideration is therefore that no older person becomes so dependent that promoting independence is impossible or unimportant. For this philosophy to succeed, focus must be on the individual in assessing and determining any need for support. Indeed, such a philosophy seems to be inherent in the efforts of the National Service Framework for Older People to combat age discrimination. The same can be said of the Age Positive Campaign. Bearing this in mind, the following two sections consider policy and research recommendations arising directly from the review.

### 6.1 Policy

The primary and eminently sensible policy recommendation arising from this literature review would seem to be that policies to promote independent living in later life should be **user-centred**. There is a simple logic behind this recommendation, which is underlined time and time again by the research covered in the review, namely that independence means so many different things to so many different people that generalisations will undoubtedly lose precisely the individuality of independence that they seek to address.

Having said this, however, there are within the different areas of independence a number of issues highlighted by the reviewed research that could profitably be addressed by policy makers and practitioners.

**Control and empowerment:** The implementation of the 1990 NHS and Community Care Act brought with it marketisation characterised by the purchaser/provider distinction, self-provision and quality assurance. And with marketisation comes the expectation that older people behave as consumers. Although some older people do see themselves as critical consumers, their power is limited in fact and the idea of empowerment rather meaningless. Neither home care recipients nor care home residents feel particularly involved in care delivery processes such as assessment, care planning, and review (Oldman & Quilgars 1999). Therefore, it does seem particularly relevant in regard of this central theme of independence that active steps are taken at all levels to combat ageism and promote a philosophy of equality and dignity and self-determination in later life.

The quality assurance systems introduced to enhance standards of care may in fact inhibit quite dramatically empowerment. It is suggested that the language of quality assurance and the professionalism of the 1990s has strengthened ageism in social care (Oldman & Quildars 1999). The effects of quality assurance systems on undermining empowerment of older people should be addressed.

Ratzka (1986) points out that the fragmentation of services causes a sense of alienation and powerlessness in the consumer, concluding that a system that permits more input from the individual consumer would most likely be more responsive to his or her needs and would enable the consumer to be more active, thereby enhancing his or her contributive power and control. These considerations should be addressed in policy to empower older people as consumers.

***Living arrangements and housing:*** Both future and present generations of older people note the importance of home and of staying in their present home as they age and even become more frail, which underlines the feeling that services should go to the older person and not vice versa (Leeson 2001a, Daatland 2000). However, the choice of present home as the most desired in old age may also reflect a lack of knowledge of suitable alternative living arrangements, or it may even reflect a denial/fear of old age and dependency, which is portrayed by the living at home / living in a home dichotomy. Therefore, it seems pertinent to suggest that steps be made to inform both present and perhaps especially future generations of older people of the alternative forms of housing in later life available. Such alternative forms of housing should take into account the diversity of older people's financial situation. However, noting the strong desire of people to remain in their present home, measures should be implemented to give access to adaptations so that mobility in the private sphere is maintained.

Residential care and sheltered housing combine both housing and care for older people. An overview of the newer forms of enhanced sheltered housing examines the claims that they can reduce reliance on or even replace residential care (Oldman 2000). Registration and funding need to be considered separately and regulation should be user-centred. Older people should be charged individually for accommodation, living costs and care and support services, thereby giving them a wider choice and a greater degree of control and enhancing their independence.

***Financial security:*** Both young and older people have great difficulty assessing the scope of their financial security in old age (Leeson 2001), which would suggest that reliable independent sources of financial counselling should be promoted.

The uptake of State benefits may rely not only on the knowledge of the different types of help available but also on the best way to access these services (Kempson et al 2002). This lack of knowledge about services and how to access them is a major reason for needs remaining unmet with regard to support at home in general (Scottish Executive 1999). Furthermore it has been estimated that in 2000/2001 between 450,000 and 670,000 pensioners may have been entitled to MIG but not claiming it <http://www.dwp.gov.uk/asd/irb.html>. There is clearly a need for dramatic improvements in information channels and in ensuring that information is both received and understood.

It is striking that work on the revision of pension schemes rarely addresses the problems such actions may have on individual low-income older people. Pensioner poverty is an area which deserves both more research and certainly the attention of policy makers. Whetstone (2002) paints a harsh picture of how those older people dependent on a state pension and income support are forced to make difficult choices to survive. Little is known of life as an older person on a low income with studies of this nature rarely focusing on older people at all. The majority of problems faced by this group seem to be the result of inadequate public policies - poor service and long waiting times in the national health service. Their housing location in deprived areas combined with their fear of crime also prevents them from taking part in activities outside

the home. A total lack of financial independence leads to lack of choice and an existence apart from others. The vicious circle of their poverty trap is striking. Policy steps to counteract this vicious circle by facilitating social inclusion should be encouraged. This could entail both the independent and the voluntary sectors as well as the public sector.

***Social and familial networks:*** The changing structure of families in ageing societies does not mean that the role of families in supporting older people is decreasing in importance (Harper 2003). The family does in fact seem to be more important today for middle aged and older generations than was the case 10-15 years ago (Leeson 2001). In contemporary society, there are, however, many competing demands on and roles for family members – one of which is care-giving, for children, spouses, parents, parents-in-law, and perhaps even other family members or friends. Comprehensive European studies of the family care of older people (Le Bris 1993; Leeson & Hoffmann 1993; Leeson et al 1993) reveal the complex aspects of this phenomenon both for the caregiver and the cared-for and the cultural settings. The size and density of a social or familial network are not per se positively linked to perceived support. Large, closely-knit families can be sources of intrusiveness, bad advice and conflict as well as support. Indeed, there may even be an inverse relationship between the size of the network and receipt of support. Pickett et al (1993) indicated that potential supportive resources sometimes may have an adverse effect. The family as a supportive network is taken for granted, despite the increasing societal burdens placed on the changing family. The family should not be taken for granted and nor should it be regarded as the obvious and most desirable supportive network for all older people. Where the family wants to be and is wanted to be the supportive network, policy must ease the burden on the family in terms of both financial but also practical support.

The loss of comfort and affection are revealed by some Dutch research as decisive factors determining frail older people's orientation towards moving into a home (Steverink 2001). This is particularly important in relation to the interrelationship between formal and informal care and how this interrelationship can enhance or diminish this orientation. Both formal and informal care were found to affect orientation significantly, but they did not counteract loss of comfort. While informal care does not apparently reduce comfort's effect on orientation, formal care actually seems to enhance the effect. This is explained by summing that older people in receipt of formal care will have little comfort and little affection and therefore over and above receiving formal care these older people will also be inclined to consider living in a home. The conclusion then is that formal care will not delay a move into a home – quite the contrary. The most conclusive policy recommendation from the paper is that formal care - capable only of providing comfort - should support informal carers in their task of providing the affection that formal care cannot give.

***Health and social care:*** Paying regular home visits to old people in their own homes has proved to be beneficial for their quality of life (Hendriksen et al 1984) as well as acting as an effective preventative tool as far as inhibiting the transition of older people into dependence is concerned. Such visits contribute significantly to reduce acute hospital care. Clearly, this is an area where policy needs to support local initiatives to promote such preventative measures.

In a qualitative study among older people receiving home help services prior to the transition to home care in a London Borough, Godfrey (1995) found that there was a clear desire by many to struggle with personal care tasks rather than receive help because being able to carry out these tasks – painful and time-consuming though it may be – was regarded as enabling them to remain

autonomous. On the other hand, they were happy to receive help with housework, as this did not threaten their feeling of independence in any way. These results would seem to support the suggestion that preventive services should be supportive in helping older people compensate for frailty while maintaining autonomy.

*Having a reasonable quantity and quality of social relationships is essential for mental and physical health, and social and productive activities that involve little or no enhancement of fitness lower the risk of all causes of mortality as much as fitness activities do* (Martin 1997). The beneficial effects of fitness activity may therefore derive as much from the incidental social and purposeful activity involved as from the effect on cardio-pulmonary fitness.

Self-rated health has frequently been used as a substitute for clinical assessment and as a basis for use of health services (Fylkesnes 1993). Physical activity proves to be a significant predictor of self-rated health, and perceived physical self-efficacy explains self-rated health status even after controlling for age, gender, living arrangements, and chronic diseases (Parkatti et al 1998).

What is being said here is that almost any kind of social activity is better than none in terms of promoting quality of life in later life. It seems, therefore, eminently sensible that general policy development should facilitate older people's social activity. This entails policy addressing a broad catalogue of issues ranging from transport to housing to financial support to family support.

## 6.2 Research

The research considered in this review reveals most certainly two clear general points with regard to the needs for more research.

- The first is that although there is both quantitative and qualitative research to be found that elucidates independent living in later life and the factors enhancing and inhibiting this independence, there is a need for more focused **qualitative** research, which is able to encompass the individuality of independence in its design and include the aspect of life history so decisive for understanding the transitions made during the life course.
- The second is that although there is both cross-sectional and longitudinal research, there is a need for more focused **longitudinal** research. As it is, the existing longitudinal studies have rarely been designed with independent living in later life as their point of departure<sup>3</sup>.

A number of areas would benefit from more exploration and research.

- Because independence versus dependence is a question of vulnerability and of transitions, it is essential that research should focus on both users and non-users of service support. The non-users may be in similar situations as users but have a compensation strategy, which enables them to remain independent.

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<sup>3</sup> The English Longitudinal Study of Ageing was published in December 2003. (Institute for Fiscal Studies 2003). This examines the health, income and lifestyles of a sample of people aged 50 and over. The second wave of data should be available late 2005.

- Longitudinal, qualitative analyses of these groups with a variety of socio-demographic-economic backgrounds would provide valuable information on the strategies engaged and the barriers encountered (some of which could be addressed by service support).
- Such studies could also elucidate the changing value over time assigned by different groups to different tasks with a view to maintaining independence, as well as investigating the role of formal support when other avenues of support are out of the question (informal support, independent paid help).
- Additional dimensions, which should be addressed in such studies, are the interactions between different support systems (formal-informal-private-voluntary) in relation to enabling and/or maintaining independence within and across different ethnic groups and different localities (Godfrey 2001).

The research carried out for this literature review reveals the significant body of research on old age and older people. It has also become apparent that *independence*, *inter-dependence* and *dependence* are key issues at the individual and societal level. However, there is a predominance of quantitative research based particularly on traditional survey methods on both large and small scales. While these studies do indeed paint a detailed picture of old age and ageing and the factors affecting the ways in which older people in different settings cope with ageing, there is a feeling that the detailed picture is rather devoid of the colour provided by in-depth qualitative studies allowing older people themselves to be more at the forefront of the research as individuals. Doubtless for a variety of both financial and practical and time reasons, there is a limited amount of national research, the majority focusing on smaller geographical areas or specific groups of older people. Therefore, it seems sensible to consider the possibility for more national research of both a quantitative but especially qualitative research into *independence*, *inter-dependence* and *dependence* which has a holistic approach acknowledging that life-course events and development influence one's ability to cope with ageing.

The factors identified as being relevant to independent living in later life do not appear equally weighted in the accessed research.

- There is substantially more work on health and social care and on living arrangements than there appears to be on mobility/transport and financial security which specifically addresses independent living per se.
- The emphasis in recent decades in terms of economic research in ageing has been focused decisively more on pension schemes and pension mixes and the macro approach rather than adequate incomes in relation to individual aspirations and possibilities.
- Research on independence in later life and ethnic minorities is under-represented.
- There does seem to be an increasing amount of research related to the empowerment of older people both at the collective and individual level, which is encouraging in as much as control and participation in decision-making are identified as key factors contributing to a maintenance of independence, even in institutional settings.

It would therefore seem sensible if future research attempted to rectify this over/under representation of certain research areas/issues. Particularly the barriers to independent living need to be addressed in future research, and in-depth life-course qualitative research which includes both retrospective and prospective elucidation of barriers would prove useful here.

As will appear from the reviewed literature, there is a relatively large proportion of the research, which is qualitative and based on small-scale populations in local areas. This does of course by

no means exclude the work from a review of this nature, but it would be advisable to suggest that more generalisable research be carried out to substantiate the conclusions drawn and referenced here.

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