

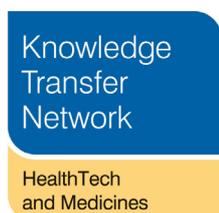


Assisted Living Platform - The Long Term Care Revolution

This report outlines the case for a revolution in long term care and captures some of the supporting material that has aided the development of the Technology Strategy Board's 'long term care revolution' programme. It includes evidence about the views of older people and their carers in the UK, lessons from abroad, the implications for industry/providers and makes recommendations to government and industry leaders.

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Executive Summary: Assisted Living Innovation Platform - The Long Term Care Revolution

Aim

The aim of this research is to outline the case for a revolution in long term care all to be set in a time scale of 2012, 2020 and 2050. This includes evidence about the views of older people and their carers in the UK, lessons from abroad and the implications for industry/providers.

Methodology

We are a multidisciplinary team with expertise in both quantitative and qualitative methods. We undertook desk-based research of reports and peer reviewed articles from the UK and elsewhere (mainly Europe). Findings are based on evaluated initiatives although we mention other promising developments.

Our philosophy

Our vision is based on radical alternatives to traditional long term care provision as well as revisiting more conventional ones. It reverses the current view that, with increasing frailty, older people are less able to care for themselves and need to become the objects of care. Our premise is that any future model must promote independence and place the older person centrally as their own designer of care. Independence does not rule out being dependent on others, on equipment and on technology for some – perhaps many – aspects of daily living. What matters is that the management of help is executed by those who acknowledge that the older person chooses a solution that suits them. The initiatives under the Technology Strategy Board initiative 'Independence Matters' can help, as can the choice of a personal budget and direct payments.

Important issues to be considered

The findings are set in the context of demographic concerns about the rise in numbers of old, especially very old, people, increased prevalence of long term conditions, more older people in employment (which can have both negative and positive effects), rising expectations, the role of informal carers, numbers in institutions and costs, poor care both in institutions and at home, financial constraints and the complexity of funding.

The findings and key points

We identify practical evaluated examples of care provision (best practice, innovative and disruptive from the UK and elsewhere - mainly Europe). Our research examines the extent to which examples enable the older person to be at the heart of any decisions on their care - a person-centred approach. We give practical examples of long term care at home by examining possible scenarios for people on the margins of institutional care. Here we build on previous research done for the Royal Commission on Long Term Care in 1999 and update this. In our updated six vignettes describing levels of disability and care needs, we look at what these people would need to remain at home. For many, help with tasks such as personal care are needed for 52 weeks a year, but technology can play a role.

The importance of home and the key role of housing. Many health conditions are related to poor housing and the housing/health link becomes more important with age as people become more prone to falls and susceptible to cold or damp. Appropriate housing is shown to have a preventive role. The growing percentage of older people who are owner occupiers may lead to them being unable to undertake repairs and renovations in the future. For those able to remain in their own home we underline the key role of home modifications.

Arrangements for older people to share a home are promising, especially cohousing, and we give detailed findings about this mainly from Europe. Other schemes such as an older person living with an unrelated family known as Adult Placement schemes have the potential for the older person staying in a homely environment. More research on both the practicalities and the advantages and disadvantages of these schemes is needed.

For older people who have to move, research shows the value of extra care housing which enables older people to have their own front door but also help on hand. Extensive research on this in the UK shows the value of this, including for people with dementia.

On technology, the findings show great potential but we caution about the hype attached to some. Simple gadgets and the greater use of mobile phones, computers and television would enhance people's lives and should be promoted more widely. Looking ahead, the next generation will benefit from greater use of this and more sophisticated technology. We also caution about the ethical issues of techniques for surveillance such as hidden monitors.

Recommendations: in general

- More attention to putting the older person at the heart of any decisions about their future;
- More emphasis on the key role of housing and specifically expansion of extra-care housing;
- Greater investment in home modifications;
- Greater attention to the status, pay, training and attitudes of staff and links between individuals and providers;
- Expansion of technology products, especially inexpensive (often low tech) ones such as kitchen devices, mobile phones etc;
- More use made of care homes for people in the community to use;
- More homes to be designed to Lifetime standards and age-sympathetic design of towns;
- Acknowledgement of both the contributions and limitations of informal care;
- Changing public attitudes, which may include an acknowledgment that more resources are needed, more use of the private sector and measures to challenge age discrimination;
- Greater information on options both for remaining at home but also for moving.

Recommendations: for the Technology Strategy Board and Industry

- A strong case be put to the Treasury and the Technology Strategy Board to invest in more services, products and research on the grounds that this will save money on expensive care but also that it will bring growth in new markets or expand existing ones;
- Specifically for industry, the production of a short summary of the potential for investment in e.g. Lifetime homes, extra care housing, co-housing projects, new technologies and the marketing of existing ones. Some of the UK schemes could be showcased.

There is need for more research in certain areas including:

- Dementia;
- Promising initiatives that have not been evaluated, including outcomes;
- Designing homes where older people live with their families in separate parts;
- Disability trajectories of older people and how best to manage changes in care needs;
- Monitoring the proportion of disabled people whose care needs are not met;
- Many aspects of technology including how to involve older people, from the design to the marketing and why older people do not use technology;
- Case studies of countries which seem to offer promising initiatives.

Assisted Living Innovation Platform – The Long Term Care Revolution

1. Background

A revolution ‘A great and far reaching change’ (Pocket Oxford English Dictionary, 2005, p.777). The Institute of Gerontology (IOG), King’s College London was commissioned in August 2012 to research a new vision which would revolutionise long term care (LTC) for older people. Based on their own extensive research, and that of others, they are committed to the underlying view that the current model is unfit for purpose, undignified and unsustainable.

The case is put that will allow the Technology Strategy Board to invest in a future programme of research and to persuade the Treasury of its importance. Part of this will be the case for changing public attitudes to allow greater investment but, more importantly, in different ways that better reflect the views and desires of both younger and older generations. This may mean new providers, new ways of doing things, more person centred services, innovative solutions (including the use of technology), new design, new products, different staff and training and a change in public attitudes. It is interesting that the terminology of social care is also beginning to change. For example, the Director of Care Services of the Joseph Rowntree Foundation stated on 23.11.12 ‘State of care in Britain – we need a revolution’ (Kennedy, 2012).

Since the present basis for provision of care for older people is founded on the premise that, with increasing frailty, older people are less and less able to care for themselves and need to become the objects of care by others, any new argument has to find ways of reversing this ideology. One reversal would be to say that any future model must place the older person centrally as the designer of their own care. This has been declaimed already but has been interpreted as carers doing their best to respect the older person rather than following direct or implied requests. There will be many who will say that this is fanciful, but becoming the object of care, whether in a home or with home care, is what older people dread. Even very frail people can remain in charge of significant aspects of their domestic lives if carers, both formal and informal, can be persuaded and then encouraged, to relinquish controlling care patterns. Independence does not rule out being dependent on others, on equipment, on technology for some – perhaps many – aspects of daily living. What matters is that the management of help is executed by those who acknowledge that the older person initiates any request or instruction.

We identify practical evaluated exemplars of provision (best practice, innovative and disruptive) from the UK and elsewhere (mainly Europe).

2. The vision is for alternatives to institutional care

The shortcomings of institutional care have been documented and deplored since the early 20th century, with the need for reform given new urgency by Townsend’s (1962) seminal study of residential care homes for older people. Deficiencies that have been slow to change include lack of privacy and personal space, while the possibilities for social interaction, engagement with the wider world and re-ablement to return home remain scarce. Moreover the insidious effect of institutions in stifling individuals’ agency and capacity for self-help remained. As Peace et al. (1997, p. 40) noted, for older people ‘the institutional option casts a shadow of deep anxiety and uncertainty in later life, as they fear its imminence’. Successive governments since the 1960s have attempted to reform residential care by incremental measures and more radically since 1990 by shifting more care into the community. The aim has been both to improve the quality of life for disabled people and to reduce the mounting cost of maintaining

residential institutions. Therefore a key criterion in assessing innovative ways of providing care in the community is whether the scheme promotes health and independence and/or delaying or avoiding entry to institutional care. Policy statements have endorsed the need for dignity and a high quality of life to be maintained through the delivery of LTC, although the resources have not always been sufficient. Reform efforts have been partially successful, especially in the case of younger people moved into, or remaining in, the community. Yet by 2000 some 300,000 older people (about 4% of those aged over 65) still lived in residential care homes and about 200,000 in nursing homes, where numbers were increasing due to closure of long-stay hospital beds. Among care home residents, about half had some cognitive impairment, a third of these being severely affected. Nevertheless, it is likely that some of today's care home residents, and many of those who might otherwise be admitted in future, could live in a non-institutional setting especially if services were pro-active rather than reactive.

The case for revolutionising LTC is based on understandings of how older people want to live when they come to need help, sometimes very high levels, with everyday life. Studies of LTC in the post-war decades indicate that older people and their families want to maintain their former lifestyle as far as possible, maintaining into old age the sense of self and autonomy for which everyone strives across the life course. This principle generates criteria for assessing how far existing and innovative schemes outlined in the subsequent section 9 (*Living environments for the future*), are likely to be successful in maximising autonomy, control and continuity of selfhood. Some of the schemes we have explored are in the UK, others elsewhere in the EU. Most of them, however, still accommodate and/or help quite small – even elite – groups.

3. The aim of the research

We were asked to outline (including evidence about the views of older people and their carers in the UK, lessons from abroad and the implications for industry/providers), the case for a revolution in long term care all to be set in the time scale of 2012, 2020, 2050. In more detail we were asked to base this on a vision of 2020 but also 2050 (desk research based on the UK and mainly Europe). This included: summarising the current position of long term care noting the problems and previous attempts to change the system, summarising the challenges of the present system, consider living environments for the future based on the projections for the numbers of people living with dementia, age-related disabilities and/or long term condition, consider some radical alternatives to institutions and build a social case for local as well as national provision, community involvement and the integration of informal care. And identify practical exemplars of provision (best practice, innovative and disruptive) from the UK and elsewhere (mainly Europe). Our findings are restricted to evaluated initiatives, policy documents and official reports. We touch briefly on some points so as to allow more time on others which are more disruptive.

4. Issues to be considered

We summarise below some of the main issues.

a. Demographic concerns and the scale and nature of likely demand

The starting point for looking at the issues has to be the demographic one. The 2011 census for England shows that the % of the population aged 65+ was 16.4%. This is the highest seen in any census. More important than the growth in numbers of older people is that of the very old. The numbers of those 90+ were 13,000 in 1911, 340,000 in 2001 and 430,000 in 2011. For many the need for support and care may be for an intensive period at the end of their lives.

b. Increased prevalence of long term conditions

A long term condition (LTC) has been defined by the Department of Health (DH) in *Long Term Conditions Compendium of Information* (DH, 2012a) as 'a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies' (ibid, p. 3). The report states that people with these conditions account, among other things, for 50% of all GP appointments, 64% of all outpatients appointments, 70% of all inpatient bed days and that this 30% of the population account for 70% of the spend. They go on to show the rise in these conditions. For example between 2006 - 07 and 2010 – 11 the numbers affected by cancer rose by 79%, chronic kidney diseases rose by 45%, and diabetes and dementia by 25% (ibid, p. 5). In addition having a long term condition usually reduces people's quality of life, particularly through having chronic pain (ibid, p. 13).

c. More older people in employment

There is expected to be a growth in the numbers of older people working into old age which will have advantages (such as more spending power) but possible disadvantages (if the job is stressful). This extra time in work has to be balanced by demands on their time from elderly parents, children and grandchildren. In addition the world of employment is changing dramatically. The growth of unemployment will have a knock on effect on the next generation of older people.

d. Rising expectations

Rising expectations, especially of the new generation of older people who are now baby boomers are not necessarily a problem but do present challenges.

e. Informal carers

Although recent research and reports advocate a change in the philosophy and provision of care for older adults, families are still a necessary resource to organise and provide care to frail older members. Adult care has been, and still is, preponderantly provided by family members (Victor, 1997; Leitner, 2003; Fink, 2004; Haynes et al., 2010). About 6.5 million, 13% of the adult population, provide care, 40% of these caring for parents/in-law and a quarter for a spouse. Caring peaks at age 50-59 but over 12% of those aged over 65 provide informal care. Women are more likely than men to be carers in midlife, while spousal care in later life is more gender-equal. This constitutes the informal care system, a resource estimated as worth £119 billion per year, more than spending on the NHS. The great contribution of carers is often acknowledged by public authorities (Pavolini and Ranci, 2008) and we refer to this throughout the report.

Yet carers continue to receive inadequate practical or financial support, leading to stress that takes its toll on their own health. According to a recent briefing, caring is linked to declining physical and mental health of carers, damage to their social relationships and isolation (Carers UK, 2012). The 2 million providing over 20 hours of care per week also risk impoverishment in midlife, finding they cannot juggle paid employment with caring and must reduce working hours or (for one in five carers) give up their job. As women are increasingly engaged in the formal labour market in midlife, many face substantial loss of earnings and future pensions when they take on informal caring. Alternatively, if they maintain employment until (the rising) state pension age, this leaves a proportion of frail individuals at risk of insufficient care (Lewis et al., 2008). Low income and financial worries exacerbate the stress of caring and many carers have to ignore their own health problems due to difficulty in finding or paying for substitute

care (Carers UK, 2012). Despite carers' rights to an assessment of their own needs, not all received this in 2006-7 and of those who did only half received any service. Moreover, of the £150 million granted to LAs for carer breaks and services, only a quarter of the annual amount was actually spent on this (Moran et al., 2012). Carers' involvement in planning Personal Budgets was found to be helpful but where carers managed the budget it placed extra work on them. Where the older person held the budget this could sometimes strain the relationship: 'Interdependencies between budget holder and carer are not easily accommodated within the model of personalisation' (Glendinning 2011, p.19).

Local Authority (LA) social services cannot meet rising demand for domiciliary care without increased funding, yet their grant is being cut by 7% each year. Mayhew's (2012) report on informal carers notes that the responsibility and cost borne by them will therefore increase, and sums up: 'The gradual withdrawal of the state will thus have significant consequences for demand, especially for unpaid care. This will lead to difficult choices for potential family carers between working and caring' but the impact on families of the policy shift is not always recognized (Mayhew, 2012, p. 10).

f. Numbers in institutions and costs

There is evidence that some people are in institutions, for example in hospitals and in care homes, unnecessarily. Hip fractures are the event that prompts entry to residential care in up to 10% of cases (quoted in Stirling, 2011, p. 5). Professor Clive Ballard has said 'In care homes in the 1980s, about 20 to 25 percent of people had dementia. Ten years ago it was about two – thirds, and now it is probably greater than 80 percent' (quoted in the Independent 16.9.12). Institutional care is also expensive. One study showed that, where appropriate, postponing entry into residential care for one year saves an average of £28,000 a year (Stirling, 2011, p. 5).

g. Poor care in institutions and at home

The major challenge is the poor standard of care provided both in institutions and at home. Numerous reports have identified the lack of dignity and care, which have been found in both situations. The Care Quality Commission (CQC) found that only 80% of nursing homes and 89% of residential care services were ensuring that people in their care were given help with the food and drink they needed (CQC, 2011). For institutions the challenges are not just the poor standard, including lack of adequate medical care, but the fact many older people enter them in a crisis without proper planning, many do not need to be there and some could be moved out if there were adequate alternatives. This is particularly the case for people with dementia. Older people, of whom 40% may come to suffer from dementia, occupy two-thirds of hospital beds (Morris, 2012, quoting Alzheimer's Society 2012). Not only may staff feel unable to cope with these patients but it is an expensive way of looking after people. However, 'Despite health and social care costs rising with age, the balance of care between total hospital inpatient costs and social care costs shifts dramatically with increasing age. It appears that a crossover occurs in people aged 90 and over, when estimated social care costs exceed the hospital inpatients costs' although there are marked regional variations (Morris, 2012 quoting Bardsley et al. 2011).

h. Financial constraints

Although the financial aspects of this research are being undertaken by others there are some factors which must be mentioned. These include cuts to services. Cuts in expenditure in European welfare states for long-term care are 'emphasising 'self-reliance' and replacing care

as an entitlement with targeted services' (Grootegoed and Van Dijk, 2012, p. 677). A study in the Netherlands found that 'disabled and elderly persons resist increased dependence on their personal networks. Most clients who face reduced access to public long term care do not seek alternative help despite their perceived need for it, and feel trapped between the policy definition of self-reliance and their own ideals of autonomy' (ibid, p.677).

As well as cuts in the public sector there are cuts in numbers employed in the voluntary sector. In the UK around 70,000 is a recent estimate (Corry, 2012) and 59% of charities expect the financial situation of their own organisations to get worse with only 13% expecting an improvement (National Council of Voluntary Organisations (NCVO) Charity forecast June 2012 ditto). A recent New Philanthropy Capital survey of commissioning from 3rd sector perspectives show a big effort to work differently (97% working differently or trying new things) and 75% aiming to harness the power of volunteers. But there were worries about closures and much use of reserves. The impact is likely to be on individuals, communities and families, professionals, policy makers and ultimately society. The future may lie in voluntary organisations working in consortia and with the private sector.

i. Complexity of funding

Lessons from 13 pilot projects in 2010 on the delivery and funding of public services showed the complexity of attempting to integrate each user's diverse funding streams into a single Individual Budget (HM Treasury and Department of Communities and Local Government, 2010, p. 17). Also from a citizen viewpoint, public services were often impersonal, fragmented and unnecessarily complex, due to the system driving the current arrangement of public services. In addition individuals and families with multiple needs impose significant costs on areas that, in most cases, are currently not tackled through targeted or preventative activities.

5. Why 2012, 2020 and 2050?

While the dates for any projections are purely arbitrary it is logical to start with the current date and then to think both short and long term. 2020 is often used in the UK e.g. by the Office for National Statistics in *Social Trends*. A recent Local Government Association estimate was that spending on adult social care will exceed 45% of council budgets by 2019/20 (Corry, 2012).

2020 has also been used by some government planners. For example the Housing Minister said (3.1.12) 'As we get older the last thing we want is for our properties to become our prisons. We want to be able to enjoy the comfort of our own homes in later years. But with nearly a fifth of our population expected to be over 65 by 2020, radical and urgent change is needed to ensure that the UK nations' housing provision meets the growing and changing demands that this is bringing and will bring in the future'. Whether that has been translated into action is another matter. Other government departments have used 2008 for a more immediate date. The Department of Health (DH) estimate that, while the number of people with one long term condition is projected to be relatively stable over the next ten years, those with multiple long term conditions will rise from 1.9 million in 2008 to 2.9 million in 2018 (DH, 2012a, p. 8).

Other demographers have used different dates. For example a big research project led by Mike Murphy at the London School of Economics found that in the UK the number of people over the state pension age is projected to rise by almost 40% in the next 25 years and the number aged 80 and over, where care needs are greatest, will nearly double' (Murphy, 2010).

2050 is used by the United Nations (UN) for their long term projections. For the UK in comparisons between 2009 and 2050 the UN estimate that the percentage of those aged 60+

of the total population will rise from 22% to 29% and that of the over 80s as a percentage of those aged 60+ will rise from 21% to 30% (UN 2009). Another relevant figure is that of old age support ratios. That is the number of people aged 15 – 64 (that is people of working age) per person aged 65+ will drop from 4 to 3.

We should note, however, that an arbitrary date hides differences in groups of people. While it is possible to suggest what may happen at any date older people may have a very different profile whether they are for example in their 60s, 70s or any other age (nb in some cases we have used some other dates where information has been more readily available).

6. Summarising long term care problems and reforms to address them

a. General

The rapid growth in the number of older people and the growing concerns to deliver a *dignified later life* has triggered substantial debates on reforming long-term care provision in the last three decades. Ageing populations have been accompanied by tightening public budgets and subsequently many OECD states have initiated a series of profound welfare state reforms. These two major trends have contributed to change their long-term care scenario. At a theoretical level, the latter trend – ageing populations and declining long-term care support - has focused on promoting social inclusion, justice and tackling health and economic poverty at older ages. The former has revolved around the need to endorse alternative and sustainable forms of long-term public/state provision for later life.

b. The UK

Promoting care in the community and minimising institutional care is a long-established policy aim, but in the 1980s was undermined by policy in other areas (Audit Commission, 1986). To address this, a review was commissioned (Griffiths, 1988). The report recommended that Local Authorities be funded to play the lead role in community care: assessing needs, designing ‘flexible packages of care’ and working with service providers in the independent voluntary and private sectors to expand choice. Critics feared that cuts in LA care services would increase reliance on family care, provided mainly by women who received little support as carers (Laczko and Victor, 1991). The White Paper *Growing Older* (DHSS, 1981) accepted that state services did not diminish family care and initiatives for carer support were set up. However, critics argued increased services were required to help carers (Hicks, 1988). The White Paper, *Caring for People. Community Care in the Next Decade and Beyond* (DH, 1989) confirmed the commitment to enable living as ‘independently as possible in their own home, or in a “homely care setting in the community’ (ibid, p. 3) and to ‘design services to meet individual need’ (para 3.3.3). Six key objectives were identified: a new funding structure; promotion of the independent sector; agency responsibilities clearly defined; development of needs assessment and care management; promotion of domiciliary, day and respite care; and development of practical support for carers. The NHS and Community Care Act followed in 1990. Policy Guidance urged that both service users and carers should be consulted in LA plans (DH, 1990) and the Carers (Recognition and Services) Act 1995 gave carers the right to ask for a needs assessment and receive appropriate services. The Community Care (Direct Payments) Act (1996) allowed LAs to make Direct Payments (DPs) for social care, but excluded those aged over 65 until amended in 2000 to include older people and in 2001 to include carers. Since LAs could choose whether to allocate DPs or maintain existing models of service provision, there was uneven development (See section 7).

The Royal Commission on Long Term Care chaired by Lord Sutherland recommended that 'The costs of long term care should be split between living costs, housing costs and personal care. Personal care should be available after assessment, according to need and paid for from general taxation: the rest should be subject to a co-payment according to means test' (Royal Commission on Long Term Care, 1999, p. xvii). This was not accepted by the Government although it was in Scotland. For people on the margins of institutional care, research showed the value of intensive home support, extra care housing, co-resident care and technology (Tinker et al., 1999). The Health and Social Care Act (2001, effective from 2003) placed a duty on LAs to offer DPs to all eligible people requesting it. The White Paper, *Our Health, Our Care, Our Say* (DH, 2006) proposed extending DPs to those 'lacking capacity' through allowing a 'suitable person' to manage the payment on their behalf. Personal Budgets (PBs) for social care have been promoted to enable purchase of services from any provider. PBs have no legislative basis at present but a concordat, *Putting People First* (HMG, 2007) was signed by Central and Local Government, the professional leadership of adult social care and the NHS. The Health and Social Care Act 2008 established the Care Quality Commission (CQC) as the regulator of health and adult social care services, setting out duties and powers. Service providers meeting specified standards may register with the CQC.

The Dilnot Commission claimed that the current system of institutional long term care was hard to understand, often unfair and unsustainable' (Dilnot Commission, 2010). They recommended that: individuals' lifetime contributions towards their social care could be capped at around £35,000, after which individuals would receive full state support. The means tested threshold, above which people are liable for full care costs, should be increased from £23,250 to £100,000; national eligibility criteria and portable assets should be introduced to ensure greater consistency. The recommendations await a decision by government. In 2010, plans for adult social care services were published in *A Vision for Adult Social Care: Capable Communities and Active Citizens*. Plans encompass improving outcomes through making services more personalised and preventative and by promoting a partnership among individuals, communities, the voluntary sector, the NHS and LAs, including housing. A shift in power from the state to the service user is intended, through extending the use of Personal Budgets (PBs) and maximising users' independence. By April 2013, LAs should offer PBs for everyone who is eligible, with information about care and support services, including to self-funders. In 2011 the Law Commission recommended: putting an individual's well-being at the heart of decisions; giving carers new legal rights to services; placing duties on councils and the NHS to work together; building a single, streamlined health and social care assessment and eligibility framework; and giving adult safeguarding boards a statutory footing (Law Commission, 2011).

The 2012 White Paper *Caring for our future: Reforming care and support* sets out the vision for a reformed care and support system. This focuses on people's wellbeing and supporting them to be independent as long as possible; national consistency in access to care; better information to help people make choices; increasing people's control over their care; improving the quality of care and integration of different services; and improving support for carers. The draft Care and Support Bill would replace earlier legislation and provide a legal basis for these reforms.

The consistent policy preference for care in the community needs to be matched by adequate resources. A danger is that, as LAs struggle to meet obligations within reduced budgets, too many older people will be excluded from care services if their needs are not 'substantial' or their income is above the means tested threshold. Not all communities can provide care through volunteering and the capacity of informal carers is also limited. The current challenges facing

long term care are summarised as underfunding, unmet need, means testing, catastrophic costs, over-burdened carers, local variations and complexity (Lloyd, 2011). The policies are in place but next we must 'turn the guidance and rhetoric of personalised care into a reality of everyday care and practice' (Cornwell, 2012, p. 3). This is better achieved through guiding principles and responsible leadership rather than detailed instructions that can obfuscate and distract. Good practice examples and case studies are seen as a good way forward (ibid).

c. Outside the UK

In most European countries the change in long term care policy has been away from institutions and towards home care. The decade of 1980s brought an urgent need for redesigning the archaic, bureaucratic, standardised model of institutional elder care. For most of the 20th Century, long term care responses were primarily based on providing residential care as a substitute for family care. The Netherlands, as pointed out by Baldock and Evers (1991) is a good example of a radicalised nursing care system. However, an increasing number of voices advocated new models of delivering care and support to older individuals. This new pattern was conceived as an alternative to residential care where individuals with different needs were treated in standardised rigid institutional systems of care. Arguments for more individualised care derived from the need for a more efficient and inclusive new pattern of social care provision (see for example Glendinning and Moran, 2009). An emphasis on tailoring services to individuals has been recently embedded within a much larger rhetoric of empowering individuals (Christensen, 2010), known as *personalisation*. Standard responses for a multiplicity of problems were deemed rigid and unfit for purpose. As a consequence, social care services have been increasingly designed to match dependent individuals' needs and care or support through individualised needs assessment and within the context of their own home.

This person care centred approach has been accompanied with a radical transformation of attitudes and the rise of housing options in favour of ageing in the individual's home. Older individuals show a strong preference to receive long-term care in their home rather than moving into a residential or nursing home (Friedland and Summer, 2005). These are seen negatively by individuals who express a strong desire to avoid institutionalisation mainly because of the lack of privacy (van Hoof et al., 2011). There has been a growing concern to prevent unjustified and denigrating institutionalisation for individuals with capacity to remain in the community. As a result there has been an increasing consensus that individuals should be provided with the tools and resources to promote and enhance autonomy and independence in the home (Wiles et al., 2012). Greater responsibilities have been placed on individuals, which have meant a shift from passive to active citizenship. Also, needs for health and social care are more complex and diverse. Thus, responses must be tailored to best meet care demands. As a result the *innovative approach* on social care is turning care receivers into active subjects of their care. Ideally the *self* becomes invigorated and personal autonomy is a *leitmotiv*.

The vast majority of Western countries have been strengthening home-based elderly care. There are diverse examples in Europe showing the shift of social care towards domiciliary services. For instance, Larsson et al. (2005) show how home help support has changed over the second half of the 20th Century in Sweden. As such, Sweden epitomises the transition from strong state support for residential care to a more mixed economy, and more crucially a deliberate and explicit departure from residential care provision in favour of domiciliary care services. This process started as early as 1956 and became popular during the mid 1960s when home help by municipalities was publicly enforced. The 1960s and 1970s showed a large increase in the use of home services. However, the decade of the 1980s brought concerns

about the sustainability of the system and tougher needs assessment were introduced. These changes were further applied with budget reductions during the 1990s. This transformed home help services as eligible individuals were more frail and demanded personal care. The introduction of non-public providers of eldercare under the control of municipalities reaffirmed the transition towards a mixed model of eldercare provision. Less frail individuals had to find alternative arrangements to meet their needs, whereas people with high demands were not only assisted with home help support, but also medical care. Rostgaard et al. (2011) reviews reforms in home care for older individuals in nine European countries. As such, a major emphasis on home based care is also observed in Austria, Germany, Italy, Ireland, Denmark, England, Finland, Norway and Sweden. Nevertheless, welfare state arrangements in each country are distinctive due to different historical, economic, political and social circumstances, which largely explain differences between them. What is clear is the parallel strains of ageing populations on public budgets and the transformation of social care systems introducing principles of economic and market criteria. Baldock and Evers (1991) observed parallel patterns between the Netherlands, Sweden and the United Kingdom during the decades of the 1980s and 1990s.

The development of social care systems during the 1980s was accompanied by concern about public budget spending. Although early debates about the sustainability of welfare state systems were particularly concerned about the increasing costs of the health care, during the late 1980s and more generally during the decades of the 1990s and 2000s there was a shift of attention towards the future sustainability of the *social care* public provision. The last two decades of the 20th Century have highlighted this because of the increasing growth of older people and their demands for care (Esping-Andersen and Sarasa, 2002; Hancock et al., 2007). It is argued that transnational changes in economies have led to a shift from a standardised phase of ageing to individualisation (Phillipson, 2003). Thus, the financial burden associated with an increasingly numerous frail population led to a redefinition of the social contract between the public and private sectors. The model of public service provision of the early 1990s was seen as inefficient to tackle the future demands for care.

As a result, the largest and more singular policy transformation in the area of long-term care in Europe has been the progressive shifting of long-term care provision from public to mixed models of care. This has been accompanied by the introduction of a market-oriented approach, stemming from the ideas of the New Public Management. These changes have resulted in a de-institutionalisation of social care provision. The state is no longer the sole provider and organiser of care provision and funding. Devolution of responsibilities towards other institutions such as the market or the family forms part of the new social contract of care. This shifting towards more mixed provision of care by which public provision is increasingly diminished is a consequence of debates and legislation stemming from reports such as the Dekker Report *Willingness to Change* in the Netherlands (1987), the Griffiths report in the UK (1988) and the report of the Swedish Advisory Committee on *Services for the Elderly* in Sweden (1989).

Some critics point to the 'marketisation' of care. Long term care policies have been introducing elements of the private market such as providing competition and consumer choice for individuals through for-profit organisations providing social care, (Pfau-Effinger and Rostgaard, 2011). In order to ensure availability and choice, LTC systems introduced reforms separating the funding from the provision of services (Pavolini and Ranci, 2008). To this end, cash for care schemes have been introduced in a large number of European countries. Cash for care schemes and tougher eligibility criteria are common strategies to tackle growing pressures for more social care and increasing numbers of older individuals. Individuals may gain greater

control of their care provision, but at the same time they are more responsible for managing their care funds. Thus, there has been a shift in institutional responsibilities from the state to individuals. Individuals have become part of a much larger system by which a combination of informal and formal resources are *managed*. In other words, a person care centred approach demands a much greater active involvement by the individual. *Empowering* has come with added responsibilities for individuals to co-produce care arrangements. Multiple examples can be found in Europe. The Netherlands introduced Personal Budgets in 1995 but has now abandoned this policy. Germany also introduced cash for care schemes during the mid 1990s; Spain on the other hand, has been a later reformer of LTC as a new law was not in force until 2006; this law also allows cash for care schemes. By contrast, the UK was one of the earliest countries in incorporating a cash transfer benefit during the early 1980s (*Attendance Allowance*). Other examples of the increase in cash transfers for dependent people can be found in Denmark with the introduction of personal budgets in early 2000s. Similarly, France has introduced cash for care payment for older people who need help with their daily activities. They are entitled to a cash benefit for a home caregiver ('aide sociale aux personnesagees: aide menagere'). In Germany, however, long-term care insurance has not stimulated the development of for-profit service providers as the preference for traditional family carers persists (Glendinning and Moran, 2009).

Another significant policy change is the distribution of social care services costs. Cost containment measures have been introduced since the early 1990s. Whereas at the initial stages home domestic care worked on a universalistic publicly financed basis, the most recent transformations have limited the contribution of the State. Individuals have been asked to contribute to a larger extent towards the total cost of the service. Thus, *personalisation* and a *market-oriented* approach, together with strains on public budgets, have shaped a system in which individuals partly or totally contribute to the costs of care. Contributions to subsidise the total costs of care services are linked to needs assessment and means testing. However, there are substantial differences between European countries.

These changes have been aimed at lowering public spending on long term care. However, as argued by Pfau-Effinger (2012), public support for long-term care has not diminished rather the contrary. Financial support has increased since the 1990s but this might be as a consequence of more individuals in need of care and/or more individuals with greater need for care for a longer period of time. The increasing number of individuals on home-based care has resulted in people living with higher levels of need and disability in the home. Thus, home based care systems have had to adapt to a much larger number of different care scenarios (Rostgaard et al., 2011). Although home care provided by public authorities has been decreasing in favour of private for profit companies, Denmark and Sweden have largely maintained their public organisation, funding and provision. However, some differences in home care between Denmark and Sweden are seen. According to Rostgaard and Szebehely (2012) Denmark has continued to publicly fund and provide care for older adults, whereas Sweden has focused more and more on targeting individuals with high care needs.

Countries that rely more heavily on family care have introduced changes more recently than countries with extensive public service support. However, whereas there exists a common agreement among clinicians, policy makers and social researchers about the desirability for individuals to remain in their home for as long as possible, little agreement, on the other hand, is found on what works best for whom.

7. Placing the older person at the heart of any solution – a person centred approach

a. General

At an international level, the United Nations (UN) have produced findings about the rights of older people (UN, 2012). Apart from their findings about age discrimination and gaps in the protection of their rights the statement goes wider than this and states that older people hold rights but are often treated as objects of charity, respect for older people benefits society as a whole (because their potential can then be capitalised) and older people are an increasingly powerful group.

Policies to place people, whether they are consumers/patients or clients, at the heart of decisions are growing. For example people with long term conditions want to be involved in decisions about their care (and be listened to), access to information to help them make these decisions, support to understand their condition, confidence to manage self care, joined up seamless services, proactive care, to be treated as a whole person and for the NHS to act as one team (DH, 2012a, p. 4). They do not want to be in hospital unless it is absolutely necessary and then only as part of a planned approach (ibid).

Assumptions should not be made about what older people feel. For example the Office for National Statistics have shown in a study of adults that those who report that they have health problems do not always report low levels of life satisfaction (Beaumont and Thomas, 2012). Nor do those with good health always report high levels of satisfaction with their lives.

Part of a new approach is the policy of 'reablement'. This has been defined as 'an 'approach' or a 'philosophy' which aims to help people act for themselves, rather than having things done for them'. Pilot projects have been set up in many areas of the country and an evaluation (Glendinning et al., 2010) has shown their benefits. An intensive short term home care intervention, usually for 6 weeks, has been made. The concept is a follow on from the practice of rehabilitation which, although there is no agreed definition, is designed to make positive impacts on individuals and carers to enable them to live their lives to their fullest potential. Also of value is Intermediate Care - nursing, physical rehabilitation and therapy to support people on discharge from hospital or to prevent admission.

As the King's Fund put it 'Patients and service users should be a part of the care team and involved in the co-design and co-production of care and health and social care staff should work flexibly in teams, making full use of the range of skills available' (Ham and Dixon, 2012, p.24).

A focus on redesigning services with the local community involved can make savings (e.g. HM Treasury and Department of Communities and Local Government, 2010, p.29): 'Telling their story to public services once' (p. 34). So can tailored support as issues emerge, rather than when they become acute (e.g. ibid., p. 36). In this evaluation Bournemouth, Poole and Dorset use data to identify older people who without a proactive offer of support would otherwise be likely to need costly services such as being admitted to hospital. Bradford estimated that by providing a single point of contact for those leaving hospital/care, improving hospital discharge planning and providing more appropriate support in the community they can reduce the number of older people being discharged directly into long term residential/nursing home care by an estimated 50% and £1.8 million (ibid, p.36).

We suggest that putting older people at the heart of any solution must start with their full involvement in planning what should be provided and how. We commend the Independence Matters programme which showed a variety of ways in which older people were contributing

to society (Design Council, 2012). While not fully evaluated yet, initial findings are promising. These included a scheme (League of Meals) which shared older people's knowledge and tips about home cooking and in collaborative cooking sessions. Another was Room for Tea which connects guests, such as interns in need of short-term accommodation in London, with hosts who have spare capacity in their homes. The After Work Club is a new social network for men who do not want to be 'retired' and empowers them to do something with their lives.

b. Personalisation and individual budgets

i. General

The policy aspiration to promote services responsive to personal needs and circumstances has been re-emphasised since 2005 with the introduction of individual budgets for service users. This approach builds on users' own agency, reducing the role of professionals (Leadbetter, 2004). The principle of personalisation has been welcomed but questions remain on how it will work for disabled older people (Spandler, 2004). We use recent research to assess this.

ii. Types of financial support

It is not clear whether the benefits of personalisation will apply in the same way to different groups with disabilities. For young physically disabled people, personalisation has been more successful than for those with learning disabilities and the mentally ill. Before outlining research on older people's use of Personal (Individual) Budgets, we sketch the elements of personalisation policy in England.

Direct Payments (DP). These are cash payments in lieu of social care services. The payment must be sufficient to buy services that meet assessed needs and may be used to employ a personal assistant (PA) to provide care; to pay a self-employed PA or for care services through a private agency; to pay a relative, neighbour or friend (but not a co-resident close family member); to buy equipment, home adaptations and other support.

Personal Budget (PB). This is a money allocation estimated as sufficient to purchase services to meet assessed needs. It is offered to all who are eligible but a conventional LA care package may be chosen instead. If a PB is accepted, the allocation can be taken in full or part as a DP, or used as a managed budget. Introduced in 2008, the government wants everyone eligible for social care to have a PB, preferably taken as a DP by April 2013 (Foundations, 2012).

Managed PB. This may be managed by the user, family members, the LA, the care service provider or a broker. In theory, it may be used for personal care, aids and adaptations, cleaning, gardening, house maintenance, transport, club membership, classes, leisure pursuits or holidays. Plans are checked and approved by the LA. In practice the choices are more limited.

Conventional LA Care Package. Domiciliary care, in which carers (commissioned by the LA through block contracts) help disabled older people with washing, toileting, dressing, and sometimes meals, has been criticised as restricting older people's choices. Because of limited funding, visits are often rushed, at inconvenient times and exclude all but prescribed tasks.

Exclusion from formal assistance. In most LAs, those whose needs are assessed as less than severe are ineligible for assistance, even though this could prolong independent living. Others with severe needs may be excluded by the means test or be required to make a contribution to the cost of their care. The LA must still provide information and advice.

Research on older people's experience of Personal Budgets. Research has found that support from LA staff was crucial in ensuring older people could exercise choice and control (Clark and Spafford, 2001) while other analysts found this was especially so for those with cognitive impairments (Arksey and Kemp, 2008). Although older people are the largest adult group of social care service users, their take up of DPs was lower than for other user groups (Commission for Social Care Inspection (CSCI), 2005) and by 2005-6 was only 1.3% of users (ONS, 2007). To find out why and to assess the effectiveness of PBs, pilot projects were carried out in 13 English LAs, from 2005-7 (Glendinning et al., 2008; Moran et al., 2012). Older disabled people were randomly allocated to a PB or a LA care package, thus avoiding self-selection bias. In the PB group, most used it either to buy basic mainstream services (home care, meals, equipment and adaptations, 53%) or for personal assistance (41%). A small minority included other options such as leisure activities. All required support from LA staff in planning and costing options and allocating their budget.

After six months, older users' satisfaction with PBs was lower than for other user groups. Nearly half of older PB users said their view of what they could achieve had not changed, compared with less than a third of younger PB users (Glendinning et al., 2008). Worryingly, 45% of older PB users had poor psychological ill-health, compared with 29% of the comparison group. There was no significant difference in meeting needs but older people 'did not appear to experience the higher level of control with IBs reported by younger age groups' (ibid, p. 87). For psychological wellbeing, 'standard arrangements look marginally more cost effective' than PBs (ibid, p. 110). In the same study, 40 older people were interviewed in depth (Moran et al., 2012). Some found managing their care services burdensome, others that the PB was too small to use as they wished and not worth the extra work. Among the tiny minority choosing a DP, some were anxious about the paperwork, the responsibilities of employing a PA and the consequences if the employment relationship broke down. Some older people did not want the responsibility of increased choice and control: 'quite happy with the arrangement I've got' (ibid, p. 16). The authors suggest that those who do want more choice and control prefer it within a conventional LA care package, for example choosing the timing and tasks when carers visit. But these would push up costs. Recent research in one LA found the average PB allocation for older people was £243 per week, twice the cost of a conventional care package but only 75% of the average PB across all user groups (Woolham and Benton, 2012). Older people who had chosen a PB had slightly better psychological health than those with a conventional care package, but the authors ask whether the LA package would have produced superior outcomes than PBs if funded at the same level. Analysis of national datasets show a fall since 2007/8 in the amount of homecare services provided to older people, with high levels of unmet need for social care; for example, two thirds of those with difficulty in dressing and half of those needing help with bathing had no support (Vlachantoni et al., 2011). These findings raise concern about LA spending cuts, if lack of social care worsens older people's health, undermining independence and shifting costs onto the NHS.

The relatively low amount of older people's PBs could make care services by community microenterprises financially non-viable, especially if they are to recruit and retain suitably trained care staff (Glendinning, 2011). Thus older people's choices in use of a PB may be very limited. A further issue is that lack of Criminal Record Bureau checks on privately-hired care staff pose a risk of financial or other abuse of older people, if the labour force is unregulated and mainly unqualified. In the absence of care management by LA social services, family members (if any are available) could be left struggling to monitor the situation. Reflecting on personalisation for older people, Glendinning et al. (2008) suggests that gains from increased

opportunities for choice and control may be very small, or outweighed by potentially significant costs. Unpredictable disability trajectories, with complex and changing needs for support, require constant review and renegotiation; the effort this entails adds to the stress for users coping with painful and distressing conditions. LA staff help in supporting older users' choices as their needs change is likely to remain important to users and their relatives.

The aspiration to improve choice in social care for older people living at home depends on adequate resources to pay for a diverse range of services and high-quality personal care. It is suggested that personalisation will stimulate an 'expanding market estimated at £21.4bn a year, or 1.6% of GDP' (Technology Strategy Board, p. 2). This market would be funded either by an older population wealthy enough to purchase high quality personalised care privately, and/or extra money from the state to enable poorer older people to purchase such care. Neither of these seems likely. State spending on care and support for older people, far from rising, is expected to be £250 million pa lower in real terms in 2014 than in 2004, despite numbers of older people rising by two-thirds (Glendinning, 2008). While the vision of independence, choice and control may be realised for better-off and less disabled older people who, although ineligible for state help, can buy what they want from local small businesses, those who are older, more severely disabled, poorer and living alone (mainly women) could find their PB too small to buy the amount and quality of care preferred. The research we have reviewed indicates that personalisation without additional resources will not achieve the desired revolution in home care for older people.

8. Practical examples of long-term care at home – the vignettes

In what follows we build on previous work for the Royal Commission on Long Term Care which looked at alternatives to residential care in institutions for older people on the margins of entering long term care (Tinker et al., 1999). This examined evaluated options and considered four in particular. They were intensive home support, co-resident care, very sheltered housing (now more often known as extra care housing), and assistive technology. We consider six vignettes of people who were on the margins of institutional care and what services might be needed to keep them at home taken from the Royal Commission on Long Term Care. The vignettes shown below illustrate the kinds and intensity of help older people are likely to need. We have added one or two extra services based on newer services available (in italics). Despite expected advances in health and longevity, similarly complex and challenging conditions are likely to continue to affect future cohorts of older people and their families, for short periods or for several years. The comment and analysis associated with each vignette showed the frequency of help (largely to make predictions about cost) but this approach may not meet the aspirations of older people, or close family members, hoping to retain an accustomed way of life and a measure of autonomy.

- **Vignette 1.** Woman aged 75-84, recently widowed and living alone. She has a supportive neighbour who is in full-time employment. She has some restrictions on mobility and moderate confusion. She is unwilling to go outside by herself now and is unable to go shopping alone or to collect her pension. She has long-interval needs (i.e. 'unable to perform one or more domestic tasks which require to be undertaken occasionally but less often than daily').

We estimate this person needs the following services:

- Day and night care: day centre 1 day per week for 52 weeks;
- Personal care/household/shopping/finance: home care 2 hours per day 7 days a week for 52 weeks and bath assistance 1 hour per week for 52 weeks;
- Care management: 52 weeks.

- **Vignette 2.** Man aged 85+, living alone. He is prone to falls and is a recent widower, not used to performing any domestic tasks. Cooking, cleaning and doing the laundry are problematic for him. He is lonely. He has short-interval needs.

We estimate this person needs the following services:

- Home environment: alarms and *falls detector*;
- day and night care, day centre 1 day per week for 52 weeks, lunch club 2 days per week;
- Personal care/household/shopping/finance: home care 3 hours per week for 52 weeks;
- Counselling: call 3 times a week from befriender, advocate, good neighbour, visiting warden;
- Care management: 52 weeks.

- **Vignette 3.** Woman aged 85+, living alone, and has become anxious and clinically depressed. Physically quite active but needs encouragement to leave the house and to socialise. Needs some support with domestic and self-care tasks. She has long-interval needs. *She could be a candidate for home sharing if room in the house.*

We estimate this person needs the following services:

- Home environment: alarm system;
- Day and night care: psycho-geriatric day hospital 1 day per week for 52 weeks;
- Personal care/household/shopping/finance: home care 3 hours per week for 52 weeks and help with gardening;
- Health care: community psychiatric nurse 2 hours per week for 52 weeks;
- Care management: 52 weeks.

- **Vignette 4.** Woman aged 85+, has moved to live with her married daughter who works part-time. She is mentally capable but has developed diabetes in recent years and now has terminal cancer. She has become doubly incontinent. Her daughter cannot provide her with 24-hour-a-day care but is able to provide care at the weekend. She has critical-interval needs.

We estimate this person needs the following services:

- Home environment: alarm, *telemedicine devices to monitor diabetes*, a stair lift and a downstairs WC;
- Personal care/household/shopping/finance: day care 2 hours per day 5 days per week for 52 weeks;
- Health care: Macmillan nurse 1 hour per week for 52 weeks, a community nurse 1 hour per day 7 days per week and continence supplies;
- Respite care: hospice care 1 week every 2 months (6 weeks per year);
- Counselling: 1 hour per week for 50 weeks;
- Care management: 52 weeks a year.

- **Vignette 5.** Woman aged 75-84, living alone, is mentally capable and has become wheelchair-bound after e.g. a stroke. She finds her situation demoralising and needs to be encouraged to socialise and take holidays. She has critical-interval needs (i.e. 'unable to perform crucial self-care tasks which need to be undertaken frequently and at short notice'). *She could be a candidate for home sharing if room in the house.*

We estimate this person needs the following services:

- Home environment: alarms and home sensors, home adaptations such as stair lift, ramps, doors widening, downstairs WC and kitchen modifications, battery operated wheelchair and a special bed;
 - Day and night care: day centre 1 day per week for 52 weeks;
 - Personal care/household/shopping/finance: home care 10 hours per day for 6 days per week for 52 weeks, home care 2 hours per day for 1 day a week and bathing assistance 1 hour per week for 52 weeks;
 - Health care: community nurse 1 day a week for 52 weeks and continence supplies 1 day a week for 52 weeks;
 - Respite care: 2 weeks of holidays;
 - Counselling: 1 hour per week for 50 weeks;
 - Care management: 52 weeks.
- **Vignette 6.** Man aged 65-74, married and living with his spouse. His dementia is severe enough that he cannot safely be left alone in the house. He is often awake and active at night. During the day he uses the toilet frequently and needs some help and supervision. His wife has arthritis and finds it difficult to get up the stairs. He has short-interval needs (i.e. 'unable to perform one or more domestic tasks which require to be undertaken frequently, that is more often than daily').

We estimate this person needs the following services:

- Home environment: a downstairs WC and shower and safety devices such as *wandering sensors and automated doors*;
- Day and night care: day sitting 1 day per week for 4 hours and night sitting 1 night per week for 52 weeks;
- Personal care/household/shopping/finance: bathing assistance 1 hour per week for 52 weeks;
- Health care: visit by community psychiatric nurse once a month;
- Respite care: 16 weeks a year;
- Care management: 52 weeks.

9. Living environments for the future: alternatives to institutions

a. Criteria for the built environment

The material environment of 'home' influences people's activities and ensures their feelings of privacy and security through control of access. Moreover, people arrange their own space to suit their preferences, while still conforming to cultural norms. These principles are usually violated in institutional settings, where spaces are so compressed and altered as to make quasi-domestic living impossible, with privacy and control of access eroded. This distances residents from social participation, as they are no longer perceived by others, or even by themselves, as living in accord with accepted cultural patterns. But the principles may also be threatened in alternative housing schemes and even in an older person's own home as a result of the way home care is delivered. Control of access is largely lost when a stream of different helpers, perhaps from different agencies, has to gain entry. Acceptance that the provider is entering a territory belonging to and in the control of the recipient is key. This may be especially difficult when a great deal of help is called for, as illustrated in the Vignettes. It can also be difficult for providers to resist taking control when a domestic setting is transformed by the necessary introduction of specialist equipment such as orthopaedic beds, mobility equipment and other devices that can distance the householder from control of space and privacy. These issues need to be borne in kind when considering innovative technology and design of new kinds of housing.

b. Criteria for the social environment

When designing new goods and services, it is essential that the emotional and psychological impacts of becoming a recipient of care are understood. Becoming an object of care by others in itself threatens dignity and selfhood, whether care is delivered in an institutional setting, an alternative scheme or in the older person's own home. For operational reasons, the timing and nature of care tasks are often reduced to fragments which providers find manageable. The individual becomes the object of care by a number of individuals, who may be seen as 'strangers', and by the organisation providing the service – a bureaucratically-led breakdown of life. This removes the older person to a peripheral position where any sense of self becomes difficult to maintain. Feelings of control, containment, order and acceptability, a sense of self within a societal whole, are at risk and this may be invisible to providers. Any innovative service needs to disrupt the strong tendency on the part of care providers to take control, as they aim to save time and maintain efficiency. Without constant sensitivity to the older person as subject, care provision can become less than supportive of self. Staff training is vital to ensure sensitivity to people's feelings about needing and receiving help, yet such input has been minimal. The range of staff expertise required is indicated in the tasks required to support the six individuals and their families/friends illustrated by the vignettes.

The Community Care legislation of the early 1990s was followed by the *Caring for People who Live at Home* initiative. Nineteen local authorities were generously funded to design and implement home care services to meet older people's aspirations more fully than before. The evaluated outcomes (Perkins et al., 1997) are still valid. They showed the feelings of 100 users about this enhanced provision. They greatly appreciated kindness/politeness; company; professionalism/efficiency; help/hope for the future; reliability/continuity; willingness. Where problems were reported, these were due to uncertainties about timing and personnel; limited time/rushing; unwillingness/ unpleasantness; inefficiency and amateur approaches. This research shows that the way in which help is provided, and by whom, is most important for the older person. Individuals must be trained and sensitized to caregiving tasks, since their

kindness and efficiency are central to the user's experience. Providing the level of skill required to maintain sensitive service standards is costly. But if person-centred care (or personalisation) is to move from rhetoric to reality, preserving disabled older people's self-esteem, the quality of care staff is key.

To summarise, the economies of scale that have hitherto been the basis of provision have not allowed the flexibility to respond to individual circumstances, which is key if putting the older person at the centre of care is a serious aim. Training high quality care staff will also increase costs. Extending new devices, forms of housing and services so that they are available to all who need care will not by itself be enough to ensure person-centred care unless guided by the disruption in thinking and practice that this research programme calls for.

c. The importance of housing and issues of tenure

To be able to stay in a home of one's own is what many older people want. This may be literally in a home they have lived in for some time, a move to a more suitable dwelling or to something purpose built with care on hand or other options. We examine these options by looking at the ways in which this can be achieved.

But first we state very firmly the importance of housing. Although the Government has belatedly acknowledge the role of housing in the 2011 Public Health White Paper we would argue that more needs to be done. One of us has already presented evidence to the House of Lords Committee looking at the effects of demographic change (Tinker, 2012). We would summarise this by arguing that, while the clear link between health and social care has been made and there are many initiatives to support this the same is not true of housing and these services. We maintain that housing can act as a preventive service. Experts in the field maintain that 'Housing standards and suitability are pivotal to achieving these (i.e. targets e.g. to reduce days in hospital) but receive inadequate attention in health planning and the cost benefits of suitable, decent housing is under-reported' (Care and Repair, 2012, p. 4). They go on to summarise the research: 'Housing conditions have a significant and quantifiable effect on health. The Building Research Establishment quantifies the costs to the NHS of specific aspects of poor housing as over £600 million per year. Many of the chronic health conditions experienced by older people have a causal link to, or are exacerbated by, particular housing conditions. This housing/health link becomes more important with age, as people become more prone to trips and falls and more susceptible to cold or damp related health conditions. Poor thermal standards in the homes of older people are a quantifiable contributor to excess winter deaths. There have been many reports that have identified where housing spend has led to savings in health' (Care and Repair, 2012, pp. 4 -5).

The Housing Associations Charitable Trust's Fit for Living Network also give extensive evidence of the links between poor health and housing (Stirling, 2011). They quote research published by the University of Warwick which 'confirmed that the one – off costs of works to improve poor housing gives an annual financial saving to the health sector. It also found that low cost interventions provide particularly good value in terms of health and well-being benefits' (Stirling, 2011, p. 3).

It is also important to recognise a number of relevant issues for the future. These include the issue of tenure especially levels of owner occupation. Levels for people of pensionable age are currently 64% (ONS, 2011, p. 7). The Pensions Policy Institute estimate that the average level of home ownership among those of state pension age will reach 80% by 2030 (Adams and James, 2009). However, as Care and Repair have pointed out 'the number of

low income older homeowners is set to rise significantly, fuelled by two main factors – the ‘Right to Buy’ and peak homeownership generations growing older whilst many pensioners’ incomes (particularly private pensions and annuities) are falling. This means that low income and poverty will rise amongst older homeowners’ (Care and Repair, 2012, p. 2).

d. Staying in own home

i. General

The most important factor for the home is ensuring that it is suitable. Ideally it should be built to standards that would be suitable for all times of the life course. Sometimes called ‘inclusive design’ or ‘design for all’ this means design without the need for adaptation. ‘Lifetime’ homes describe homes that have been built to be adaptable enough to meet the changing needs of someone through a lifetime (See section 10a good design).

If changes are needed an occupational therapist is the ideal person to look at the home and recommend what needs changing. Disabled Facilities Grants up to a maximum of £30,000 are available on their recommendation. They are for owner occupiers or private tenants and cover work improving access to a bathroom, living room or bedroom, providing extra bathroom facilities, making the preparation and cooking of food easier, adapting lighting or heating controls and improving a heating system. We suggest that they are very good value and would help prevent a move to an institution.

ii. Home sharing

Homeshare schemes match an older householder with a ‘Homesharer’ who can provide some support and companionship - often a student or public service worker in housing need. Homesharers, who may be single or a couple, usually live rent free but contribute to household bills and provide an agreed amount of hours of help each week; shopping, cooking, cleaning, laundry and gardening. They keep an eye on the older person, providing company, reassurance, support and, if necessary, liaison with relatives. Homesharers play a preventive role – improving nutrition, ensuring drugs are taken correctly, reducing risk of falls and use of emergency services, but they do not provide personal care, which is arranged separately. Increasing need for personal and/or nursing care by the older person often limits the duration of a match but Homesharing can shorten hospital stays and delay a move to residential care.

In the UK, Homesharers are vetted by staff of a charity or statutory body, who ensure both parties accept the terms, including length of the agreement. When a Homesharer wants to leave, staff seek a suitable replacement in good time. There are no tenancy rights or contract of employment. Details of the legal, safety, insurance, financial and ethical safeguards are provided in Hardy (2011). Homesharing is available for older people with sufficient space in their home and living where a programme operates. Since the 1980s, 11 schemes have been developed, including in Greater London, East Sussex, Bristol, Bath, other parts of Somerset, Worcestershire and Cumbria; some schemes charge for matching and administration (NAAPS UK, 2011). There is a lack of independent research and evaluation of UK schemes.

Outside the UK, Homeshare schemes aimed at helping frail older people operate in many western countries. In the US, where the idea started in the 1970s, 100 schemes operate, involving both rental payment and service exchange. **Australia** has a few schemes and there are many in Europe. Schemes are similar across countries in their principles but differ in details, such as eligibility criteria to join and arrangements for exchanges of money and care.

In Australia, there is growing interest in Homeshare programmes. Home Share Melbourne, run by Wesley Mission Victoria, has operated since 2000. Homesharers range from young students to retired individuals in their early 70s, providing up to 10 hours per week of help to older householders in return for accommodation (Wesley Mission Victoria, 2012). A social evaluation of the Homeshare Victoria pilot scheme found householders applied for a Homesharer due to declining in health or hospital admission, being concerned for safety and security and wanting companionship. The duration of matches was 32 weeks on average but variable, about a third lasting at least one year. The study concluded the scheme was of significant social benefit to the participants (Montague, 2001). A cost-benefit evaluation of the same scheme estimated annual benefits worth \$832,317 to participants and net savings of \$50,222 to the health and social care system (Carstein, 2003). Home Share Tasmania, a pilot program run by a Government funded agency and covering Hobart, Glenorchy and Clarence' (Department of Health and Human Resources, 2012) requires 10 hours of help per week in exchange for accommodation. Administrative costs and a matching fee of A\$150 are paid by both parties (Homesharer and Householder) avoiding any state subsidy. However, no one is excluded due to an inability to pay.

In **Spain** schemes are usually managed by public or private non-for-profit agencies, although a savings bank has participated. A distinction is made between older householders who are relatively independent and those needing more care, although Homesharing for the latter is rare. In Catalonia, a Homesharing project matching students aged under 30 with older people over 60 has operated for 12 years. Extra benefits to students are a small payment and much-needed free accommodation, while the older person benefits from the intergenerational contact.

In other countries, such as the **Czech Republic**, the homesharer pays a small rent and provides a few hours of services while in Germany and Austria, homesharers may pay rent or provide a combination of rent and services. Often, schemes are managed by universities, or focus on matching students with older people, as in Italy (Rome, Florence, Bologna, Turin). Similarly, in France there are several programmes, including the 'Ensemble 2 générations' (a not-for-profit organisation) that matches students and older individuals under different regimes of exchange: rent or services or a mix of these (ensemble2générations, 2012).

In summary, Homesharing enables older adults to remain living independently in their home for longer, preventing isolation and saving costs to both the householder and the state in reducing use of hospital, residential care home and domiciliary services. It provides cheap accommodation for those needing it, especially students, and a bonus is the contribution to intergenerational relationships, with transfer of knowledge, experience and values between younger and older people.

iii. Home modifications

Home modifications include repairs, aids and adaptations. Largely pioneered in the UK there are many examples of evaluated successful schemes.

In the **UK** Home improvement services are agencies that provide comprehensive, practical housing help to people on low income home owners who need help with repairs and adaptations to their homes. They provide advice, help and support to repair, improve or adapt their home or move to more suitable housing if this is the best option. They are currently facing cuts in funding.

The value of Handyperson schemes that offer 'that little bit of help' have been shown in an evaluation (Croucher et al., 2012). Schemes are described in the evaluation as 'assisting older, disabled and vulnerable people with small building repairs, minor adaptation such as the

installation of grab rails and temporary ramps, 'odd' jobs (such as putting up shelves, moving furniture), falls and accident checks, and home safety and energy efficiency checks' (ibid, p.1). The research found that the services 'deliver a relatively high volume of preventive activity a relatively low cost' (ibid, p. 3). In particular the report focuses on the preventive role where small repairs and minor adaptations offer the potential to reduce demand for health and social care services.

Services could reduce the risk of falls and enable independent living, increase people's security by measures to prevent burglaries, reduce the length of hospital stay by discharge schemes that can install key safes, grab rails, temporary ramps, moving a bed etc, enable energy efficiency schemes and measures that lead to improvement in health and wellbeing. In addition the research on cost effectiveness showed that, for example, adaptations could postpone entry to residential care by a year saving on average £28,080 p.a.; preventing a fall leading to a hip fracture could save the state £18,665 on average, reduce the costs of home care saving £1,200 to £29,000 p.a. and speed up patient release, a potential saving of at least £120 per day (ibid p. 3). The research additionally evaluated some pilot projects which went beyond the traditional services by, for example, providing a more tailored service to people with dementia.

Another study endorsed these findings summarising research showing that improving people's homes produced real benefits in health and wellbeing in addition to producing cost savings (Papworth Trust, 2012). Their recommendations included a new partnership between the health care and home adaptations sectors including the involvement of the new Health and Wellbeing Boards, giving GPs a bigger role including being able to prescribe aids and adaptations, giving more information and advice, changing means testing rules and offering low interest loans for people with home equity who do not qualify for help.

For home owners with housing equity it is possible to release some of that equity to pay for repairs and adaptations. However, older people have not been enthusiastic about taking up this option as some schemes have had problems. It has been suggested that 'State support for social lending possibly coupled with some grant help is an important measure to ensure that equity release options become a viable option rather than one which is talked about as a solution but is not effectively used' (Care and Repair, 2012, p. 7).

Outside the UK an early piece of research on the impact of home modifications in prolonging independent lifestyles of older adults was in the USA by Mann et al. (1999). This assessed through randomised control trials the functional decline of a group of frail older individuals over a period of 18 months who had assistive technologies and home modifications. The assessed assistive technologies refer to canes, walkers and bath benches. Results show a lower functional decline among the group of individuals that received treatment compared with the control group. By contrast, a study by Fange (2005) in Sweden among a group of 98 community-dwelling individuals found little impact of home modifications on 'activity aspects' and 'personal and social aspects', though individuals reported higher independence in 'bathing'. Nevertheless, as Petersson et al. (2008) show, home modifications help to decrease the difficulty in performing personal, instrumental and mobility tasks. Other studies indicate positive outcomes of home modifications for older individuals on improving the sense of safety and security. For instance, Petersson et al. (2011) found significant increases in the sense of safety and security among Swedish individuals receiving home modifications. The project, embedded in a much larger research on home modifications, points out the potential of small physical changes in the home to maintain individuals' independence in their home. However, according to Fange (2005), the largest problem in comparing home modification interventions is the lack of a homogenous conceptual definition and methods to assess individuals.

Recent research was conducted in 2011 by the Social Services Department of Barcelona City Council in collaboration with the Independent Living Association (Centre de vida independent, 2012). The programme of home modification was aimed at individuals aged 65 and older who have telecare services to promote personal autonomy. A total of 911 individuals benefited from the home repairs and technical support in the home. Common characteristics of these individuals were that the vast majority had low incomes (74%), lived alone (approx. 92%) and were females (approx. 90%). Among the home modifications and technical aids were: grab bars, raised toilet seats, shower seats, long handle brushes and combs, towels for toes and back, adapted drinking cups, pan handle holders, bowls and plates with high sides, sock aids, mobile lifts, articulated beds, walkers, senior-friendly TV remote control or doorbell amplifiers. Positive effects were found regarding security, quality of life and autonomy to perform daily life activities. Another finding that shows the preventative nature of the programme is that 'The estimated rates of prevalence for each severity level of dependence for a range of ages are the same in the next lower range if a prevention programme is implemented' (Alemany et al. 2012).

Home modifications have also been reported to efficiently tackle risk factors for falls and consequently hip fractures. These are associated with greater probabilities of mortality and morbidity among older individuals (Wolinsky et al., 1997). Recent systematic research conducted by Clemson and colleagues (2008) reviewed a series of environmental randomised trials assessing the impact of home modifications in reducing falls. Home environmental programmes were found to reduce the risk of falls, especially for individuals with a high risk. On the other hand, research conducted by Lord et al. (2006) points out that home modifications are not directly preventative among the group of older individuals. The authors reviewed five randomised controlled trials showing positive outcomes, although these studies did report inconsistent findings. Similarly, Stevens et al. (2001) point out the lack of positive outcomes in avoiding falls from a one-off intervention, although the study was not exclusively focussed on home modifications but also education and hazard assessment. Thus, home modifications show mixed results as to the efficacy in improving independence and quality of life of older individuals.

Public policy aimed at funding and providing home modifications for disabled individuals varies across European countries. Nordic countries are among the most generous in publicly funding home modifications through councils and local authorities. By contrast, Southern Mediterranean and Central countries have much lower public involvement in funding and provision.

e. *Who moves and why*

We also need to address the issue of moving. In 2008/09 9% of all households in England moved within the previous 12 months and owner occupiers were more likely to move than tenants (ONS, 2011, p. 14). Older people are not a particularly mobile group but are more likely than younger to under occupy. A study in Sweden of cohorts of people born in the 1920s, 1930s and 1940s found that the majority remained in their own home but almost one quarter did move (Abramsson and Anderson, 2012). Of these a smaller number moved from owner occupied housing to a tenant cooperative or rented home. This study showed the importance of cohort differences. They say 'If the characteristics of the movers from single-family housing to apartments – such as higher divorce rates, higher education, foreign born and generating capital income for the sale of a house – are represented to a larger extent among the younger cohorts, then we can expect more such movers in the years to come provided that the types of housing in demand is available' (ibid, p. 600).

f. Moving to a specially designed home

For some people a move may take place to a specially designed home. This is usually one designed to disability or wheelchair standards. The concept of Lifetime homes pioneered by the Joseph Rowntree Foundation has been proved to be a cost effective solution in that people can stay in this kind of home for all their lives.

g. Moving to specialist grouped housing – sheltered and very sheltered/extra care housing

In the UK most specialist housing started in the form of sheltered housing. This was a group of flats or bungalows with communal facilities, a warden (often living on the site) and an alarm system. However, research showed that it was difficult to keep very frail people there as there was not enough support and some homes became difficult to let (Tinker, 1995). From this concept developed a form of housing with more support.

Extra care (or very sheltered) housing is sheltered housing with additional features such as 24 hour care on hand, enhanced communal facilities and at least one meal a day provided. The first evaluation of such schemes was a national survey in 1989 (Tinker, 1989) which found that it was 'one way in which elderly people can retain their independence and yet receive extra care'. It was considered to be one attractive alternative to most for hospital or residential care. It was popular with management, elderly people and staff. However it was 'generally more expensive than staying at home with an innovatory service though generally cheaper for elderly people than hospital or residential care (Tinker, 1989, p. 126). Subsequent evaluations have found similar findings. Key findings of the largest recent study found that the most important attractions of extra care housing were: having their own front door, flexible on-site care and support, security, accessible living arrangements and bathrooms, the size of the accommodation available (Netten et al., May 2012). The overall conclusions were very positive. It was concluded that 'People had generally made a positive choice to move into extra care housing, with high expectations, often focused on an improved social life. After they had moved in, most people reported a good quality of life, enjoyed a good social life, and valued the social activities and events on offer. Comparing residents with similar characteristics in care homes, residents in extra care housing had better outcomes and costs were not higher (ibid, p.4). However the researchers went on to caution that 'Without continuing to attract a wide range of residents, including those with few or no care and support needs as well as those with higher levels of need, extra care housing may become like residential care and also its distinctiveness'. This is the general dilemma when services are rationed to those with the greatest need.

Another study concluded that extra care is a healthy home for life, translates into fewer falls, and supports some of the oldest and frailest members of society. The researchers also looked at the possible savings in time in hospital. They state that 'Residence in extra care housing is associated with a reduced level of expected nights spent in hospital than may be expected in an equivalent population living in the community, matched on demographic and selected socioeconomic characteristics. However, the differences are attributable to a lower propensity of being confined in hospital initially, and not through shorter lengths of stay. Our findings generally support our notion that extra care may play a part in reducing the risk of initial entry as a hospital inpatient' (Kneale, 2011, p. 122). The conclusions of this study were that 'The benefits of residence in extra care housing could translate into substantial cost savings, particularly in the long-term' (ibid, p. 132).

The report goes on to make the case for more of this kind of provision. A small amount of resources have recently been made available for the development of extra care housing. The Government made available a £300 million capital grant to stimulate the market. It is hoped that this will result in an extra 9,000 special homes. Although most extra care housing has been provided in the public sector either by local authorities or housing associations there is also a case for private provision, a Private Finance Initiative/private partnerships and using developers own resources (King et al, 2005).

A note of caution about the expense of extra care housing was expressed in the recent HAPPI 2 report produced by the All Party Parliamentary Group on Housing and Care for Older People (Best and Porteus, 2012) when they suggested that it might not always be economically possible for every scheme to have a range of communal facilities and on-site staff. They state that 'For the mass of retirement housing projects the current age of austerity means 'cutting one's cloth 'to take account of more straightened times. While some space for social interaction, at least a 'club room' with kitchen facilities will remain important, it seems that in most new developments the footprint of communal space will have to contract' (ibid, p. 11). However, they also put the case for provision of 2 bedroom apartments. This might encourage older people to downsize.

Outside the UK across the world there has been a movement towards smaller clusters of housing with varying degrees of support. The ultimate purpose of small clusters was to improve privacy, autonomy, choice, control and independence of residents (Regnier and Denton, 2009). To that end, a series of new purpose-built group housing clusters have been developed in various cities in different countries. In this category of housing we can include Assisted Living Facilities (ALFs) in the **USA** or cluster housing schemes in the Scandinavian countries or the more recent 'housing with services'. These facilities are home like supportive living arrangements similar to nursing homes but with a stronger promotion of independence, intimacy and choice.

Cluster housing has a long tradition in the European Nordic countries. In **Sweden**, for instance, cluster housing or *Fokus* housing has its origins in the late 1960s. During the 1970s the Focus society built 280 apartments located in 12 cities. Most of the cluster housing building consists of 50 or 60 units with 10 to 15 special apartments for individuals with extensive care needs. During the 1980s more apartments were built, but the original philosophy of cluster housing was modified. '*Boendeservice*' are also apartments but in smaller units with fewer apartments and not shared facilities. There are only 5 to 10 apartments with round-the-clock access to staff from a separate unit (Ratzka, 1986).

Other similar 'housing with services' experiences have been developed in European Countries. For instance, in **Spain** the City Council of Barcelona has recently promoted 925 units of apartments for older individuals ('Habitatges amb serveis per a gent gran') (Ajuntament de Barcelona, 2012) that serve over 1,000 individuals. All the apartments are purpose-built homes with telecare technologies and round-the-clock staff assistance.

Assisted living facilities are particularly popular in the **United States** where there has been a rapidly growing market of these licensed facilities (Ball et al., 2004). Although they share similar characteristics with cluster housing, they are substantially different from the new Scandinavian model of 'housing with services'. The main characteristics of these facilities are their nonmedical character, 24 hours assistance and personal care services for dependent older individuals. A study conducted in various assisted living facilities in the U.S. found an overall positive outcome of living in such institutions and avoiding stressful situations of leaving

a familiar place. However, for a few residents with high needs staying in ALFs turned out to increase physical impairments and being socially neglected. Thus, ALFs are a perfect fit for certain individuals with low or mild care needs. The research by Ball and colleagues (2004) indicates the importance of managing resident decline; this is balancing needs with resources (with a consequent increase in fees).

A more recent type of residential group living developed in the **Netherlands** shares similarities with 'housing services' or 'service houses' in the Scandinavian countries. 'Apartments for life' is an innovative housing arrangement for older people boosted by the non-profit organisation Humanitas Foundation in Rotterdam in the mid 1990s. Its revolutionary concept of care, cure and community living has served as a good example for Australia. The housing project was projected as an alternative to traditional residential and nursing home care. The major purpose is to keep people independent for as long as possible in a local community where they feel safe and where their demands for care and social exchange are easily met.

Apartments for life started with 350 apartments in three complexes in 1995. It has now been expanded and has 1,700 apartments in 15 different complexes with an estimated figure of 2,500 individuals making use of it (Humanitas Foundation, 2012). These apartments offer a wider choice of care. Residents are free to organise their care needs as they wish rather than living with constrained schedules of activities and care. Apartments are specially designed for individuals with care needs ('age proof' apartments). People can continue to live with their partner or relative. These apartments can be purchased (owner-occupied) or rented. In the case of Humanitas-Bergwegdiffers in that the apartments (195 in total) are subsidised rented apartments. The Humanitas Foundation stresses the idea of 'Use it' or 'Lose it'. This idea is related to empowering individuals with care decisions. They are in charge of their daily living as long as they are capable. 'Patronisation and 'killing with kindness' are disastrous for a person's functioning and consequently for his or her human dignity' (Humanitas Foundation, 2012).

The value of extra care housing at the end of life is highlighted in section 11.

h. Retirement villages

A relatively recent development in housing for older people in the UK has been retirement villages. These are purpose built developments usually with different types of accommodation and sometimes the whole range of facilities from ordinary small homes, nursing homes, leisure facilities and a restaurant. More familiar in the United States and Australia they have proved popular with residents. In the UK most have been for owner occupation or for a particular group of people such as Licensed Victuallers. Many are leasehold and are subject to rises in service charges. There is little information about such developments in the UK apart from one or two evaluations of specific schemes such as Berryhill Retirement Village in the Midlands (Bernard et al., 2004) and Hartrigg Oaks in York (Croucher et al., 2003). Both these have been shown to be popular with the residents. It remains to be seen if they follow in the pattern of some in the USA where there have been problems of schemes going bankrupt and of people being turned out when they become frail.

In the US, New Zealand and South Africa, retirement villages for older adults are fairly common. The village model has its origin in the **US** with the construction of Beacon Hill Village (see references – website). This is a membership organisation in the heart of Boston founded in 2001. It was an initiative of a group of long-time Beacon Hill residents as an alternative to moving from their homes to retirement or assisted living communities. Beacon Hill Village enables a growing and diverse group of Boston residents to stay in their neighbourhoods as

they age and become more fragile without the need to move to a nursing home. By organising and delivering programs and services residents can lead safe, healthy productive lives in their own homes with care facilities if needed. There are also a range of social and cultural activities available to residents. According to Village to Village network (2012) there are more than 60 initiatives varying in their characteristics; they are self-governing institutions based on membership that provide and arrange services with the objective to help individuals age in place (Greenfield et al., 2012) through a 'combination of non-professional services, such as transportation, housekeeping and companionship, as well as referrals to existing community services' (Scharlach et al., 2011). As pointed out by Scharlach et al. (2011) and Greenfield et al. (2012) there is an alarming lack of evaluation and examination of village initiatives across the country. When Scharlach et al. (2011) conducted a survey of 30 fully operational villages across the US the findings were restricted to describing the characteristics of the villages, excluding any review on health outcomes or impact on individuals' well-being.

In the **Netherlands** Hogewey village was founded about two decades ago (1993) near Amsterdam (Weesp). This organisation is designed for individuals with dementia who can no longer live independently in their own home. The village can host up to 167 residents. The organisation aims at making individuals as comfortable as possible by enabling them 'to continue to live in the manner to which they were accustomed prior the onset of dementia' (Notter et al., 2004, p. 449). To that end, they have created different life styles within the village ('homes within homes'). Seven lifestyles are designed to better adapt to different social circumstances of individuals. As such, these seven styles are: Gooise or aristocracy; Culturel; Amsterdamse (urban crowded lifestyle); Indische for people from Indonesia; Christelijke for individuals with Christian religious faith; Ambachtelijke for people described as having a working class lifestyle; Huiselijke for people who were domestic workers. Each individual is then assessed and placed in one of the seven lifestyles such as beliefs, previous activity, hobbies, etc. They all have their own house and are in charge of a small budget to buy food, medicines and care supplies. There are three different groups of individuals with different needs and capabilities: mildly impaired or largely autonomous; moderate to severe impaired people with dementia who need professional supervision on a daily basis; and, bed-ridden individuals. The village offers a wide range of facilities such as a grocery, kitchen or a bar. Care is provided 24 hours seven days a week, but individuals can walk freely around the premises. According to Hurley (2012) the costs for the resident in Hogewey does not exceed the costs of a nursing home in Holland. However, there has not been a thorough examination of the cost-effectiveness of Hogewey. There is also a lack of studies reporting on clinical outcomes (Hurley, 2012).

A similar village initiative in the **USA** is TigerPlace (see references – website Americare). This innovative community-based care facility has been designed, supported and provided by the Sinclair Home care, a licensed Medicare certified home health agency and an in-home provider of supportive services founded in 1999, in collaboration with the faculty from many colleges and schools, mainly the Sinclair School of Nursing (SSNO) in Missouri. TigerPlace is located in Missouri (USA) and is the expression of a new Ageing in Place Project that aims at maximising and promoting independence for older adults (Rantz et al., 2008) using the village model in combination with smart home technologies. The TigerPlace project started in 2003 with 33 apartment units and more recently 24 more units have been added. Each apartment is fully equipped with kitchen, washer and dryer. The model of the facility is a village one for independent living. TigerPlace consists of 31 independent apartments and uses the same technology. Sensors are installed in the apartment to monitor individuals' activities. The

building offers a series of facilities for intermediate long-term care. A centralised wellness centre organises activities to help resident remain active and independent for as long as possible. The wellness centre is open three mornings a week, but all residents are entitled to use a registered nurse on call 24 hours a day. Sinclair Home care provides a large variety of in-home services such as help with activities of daily living and care coordination of health conditions. Demiris, Oliver et al. (2008) interviewed nine people using ambient technology in their apartment in the Tiger Village retirement facility. One of the characteristics of this village is the emphasis on combining community-dwelling services with home-based technologies. The team conducted 75 interviews and three observational sessions. The aim of the interviews was to look into the individuals' perceptions of the sensor technologies. The findings are very similar to what van Hoof et al. (2011) found among users of smart technologies in the Netherlands. There are three clear phases: familiarisation, adjustment and curiosity and integration. People in the study did not report privacy concerns. However, there are three major caveats in Oliver and colleagues' study. First, it does not provide evidence about the effects of the technology or benefits of community based care for individuals in terms of health outcomes or well-being. Secondly, there is a lack of research on the cost-effectiveness of this facility and whether it is affordable for the large majority of people. Finally, the findings on individuals' perceptions are based on a very small sample of only nine individuals.

i. Other options

Other options include sharing a home with a family either in a granny flat or living with the family; sharing with another older person or with a group (such as cohousing).

i. Sharing a home with a family

Some older people move in with a family or, more rarely, a family will move in with them. They may share the home and live together or may live as separate households as in Granny Flats. This is where the two households have accommodation with some of their own facilities such as a front door and/or cooking arrangements. Some early research of this form of housing in the public sector showed how successful they were for the older people and families (Tinker, 1976). They can provide mutual support and may release an under-occupied home if the older person moves. However, they were inflexible as there were problems when the older person died or the family moved. This kind of housing is more practical in the owner occupied sector where an additional home can be used for others such as an au pair or other staff, a returning adult child or let. We suggest that this form of housing should be encouraged. Little is known when two or three older people live together whether they are related (such as two sisters) or unrelated friends.

ii. Adult placements/shared lives

An older person with modest care needs can pay (including from a Personal Budget) to live in the household of a carefully matched and trained Family Care Provider (FCP) who provides an agreed amount of personal care. The matching service is regulated and may be operated by an agency such as NAAPS, a UK-wide network of very small family and community-based care and support solutions (NAAPS UK, 2010a) or a LA such as the Peterborough Adult Placement Scheme (2010). These recruit, assess and approve families, charging a fee depending on the older person's age and means. About half the matches (3,800 of 10,000) are affiliated to NAAPS under the brand name Shared Lives (NAAPS 2010a). The placement may be on a long or short-term basis, as FCPs may provide day care or post-hospital care and enable respite for informal carers. Shared Lives services are closely aligned with the

goals of personalisation (see section 7), supporting the older person to enjoy a social life and pursue independent relationships, ensuring their wishes are central in any decisions affecting them. NAAPS (2010a: 6) claims that 'Many people's wellbeing and quality of life improves dramatically when they start to use Shared Lives' while the Care Quality Commission's 2010 report rated 95% of English Shared Lives schemes as good or excellent and none as poor.

However, there are some drawbacks to adult placement for older people. Where an older person wishes to purchase extra care services from a personal assistant, they may need a 'suitable person' to manage their money and any employment contract involved. But naming the FCP as the suitable person can give rise to a conflict of interest and/or be unlawful. Similarly, if the cared-for person wished to use Direct Payments to purchase services, it would be preferable to have a family member, friend or the LA as the 'suitable person'. Modifications to the Shared Lives structure, especially where the mediating and matching role of Shared Lives staff is by-passed to cut costs, risk falling foul of legal and ethical safeguards for the participants. Details are very complex as each of the diverse arrangements possible comes under different regulations, tax regime and employment law, and these differ among the UK nations. Moreover, adult placement has been oriented towards younger people and moving to live in another household may be less suited to older people, diminishing their sense of self and the continuity of their life (see section 2). In addition, the requirement to pay for the placement (in contrast to Homeshare in the UK) introduces complexity and legal issues that can be unwelcome for the older person.

For local authorities (LAs), considerable savings can be made through placing an older person through Shared Lives, who say they save the LA £2,340 per person pa on average relative to other forms of support. But savings are made at the expense of FCPs, who are available out of hours and typically do more than they are paid for. Some FCPs have reported that cuts in LA day care services put them under pressure that impaired the quality of their support to the older person: 'They rely on us feeling guilty and providing free support'. This extra work is likely to increase as cuts in LA budgets for social care bite. A Shared Lives staff member warned, 'We're in danger of recreating bad family situations if we don't fund a proper service' (NAAPS UK, 2010a, p. 7). Although the CQC assessments of Shared Lives schemes are positive, there is no other independent evaluation.

iii. Cohousing

Cohousing denotes a self-starting, self-managing intentional community that can be intergenerational or restricted to those over age 50. Such communities are dedicated to sharing activities, keeping active and mutual support. They cater for older people who value their autonomy and privacy, yet enjoy companionship and reciprocal minor assistance. Social isolation, a common problem among British older people was found by a Swedish study to be significantly linked to dementia rates. Its advocates claim that cohousing, by facilitating social interaction within the community and through its ethos of mutual self-help, may allow older people to avoid entry to a residential care home or delay this as long as possible. The energies of older people themselves are thus harnessed to reduce demand on health and social care services (Brenton, 2001; 2004). Neuburger (2008) sees co-housing as enlarging frail older people's choices, catering for their preference to avoid a nursing home or delay entry as long as possible. In this section, we describe various forms of cohousing in Europe and North America in terms of how such communities work, their robustness, and the kind of mutual care practised. However, there is a lack of research on how communities cope when members' need for care increases.

The **UK** is a cohousing laggard by comparison with international developments. There are many affinity communities coordinated by the Cohousing Network, but as yet no cohousing scheme for older people. The Older Women's CoHousing group (OWCH) is a group of London women aged from 50 to 80 who meet regularly to plan their own cohousing community in the capital, with mixed rental and owned units. When this is achieved, it could be the first such development by older people in the United Kingdom (OWCH, 2009). But so far the UK is arguably missing an opportunity to use older people's own organizing energy and capacity for mutual aid, as well as to save costs to the state.

Co-housing outside the UK has plenty of examples. **Denmark** has about 350 collective housing schemes, mostly in groups of 15-30 units. There are also about 140 intergenerational schemes. Cohousing is located near small and medium-sized provincial towns. Senior units, each with kitchen, bathroom and small garden, are typically low terraced houses around a courtyard and sharing common facilities. Only 1% of Danes aged 50+ live in collective housing, but many would like to, attracted by the sense of community, good neighbours, reciprocal support and arranging activities together (Kahler, 2010). DaneAge (2007) estimated between 15 and 20 per cent of older people wanted to move into collective housing or senior-citizen houses. A 2009 survey of 23 seniors aged 60-90 in a cohousing scheme indicated they felt happy, safe and had better self-assessed health than in 1999. The majority were active in associations, such as evening classes or sports, and benefitted from help with small tasks and from company. Before moving in, 85% said they often felt lonely but only 10% said this in 2009. Optional communal meals, prepared on a rota basis, are shared three to five times per week (Kahler, 2010; Berger, 2010).

Sweden has 45 cohousing schemes, the result of civil society campaigns and positive responses from public housing authorities during the 1980s. The projects are concentrated in the main urban centres and are mainly in blocks of flats. Communal facilities are usually on the ground floor but may include a roof patio. Senior cohousing units are small (e.g. 8 sqm) which keeps them affordable. Units are popular and there are waiting lists. Choi's (2004) survey of residents in Scandinavian cohousing found that most were healthy, in their 70s, and satisfied with their home. It would be interesting to follow them up when they are older.

In the **Netherlands** cohousing (or *centraal wonen*) started in the 1960s, mainly founded by young people, and the number of schemes has increased since then. Each household has the normal rooms and facilities but shares facilities such as laundries, meeting places, hobby rooms, workshops and garden space. Schemes usually have 30 to 70 households, sometimes in self-managing clusters. Most are rented from a housing cooperative but some are owner-occupied (Bakker, 2009). In the 1980s, communities for seniors, '*living groups of the elderly*' were developed, to meet the needs of the growing proportion of the population aged over 50. These are supported by local government as they are expected to reduce care costs, but they are started by interested individuals and couples. The Dutch Federation of Intentional Communities commissioned a study in 2008 into the level and quality of mutual caring experienced in cohousing communities (Bakker, 2009). This author notes that individuals need to be able to cope with the conflicts that sometimes arise in making democratic decisions and negotiating on the basis of equality, co-operation and a sense of responsibility; there are no leaders. The reward is a sense of belonging, reciprocity and learning from others. Members value this form of living for its warmth and companionability (*gezelligheid*), social interaction and mutual support. Shared meals are rare but members act as friendly neighbours. Some older people choose a mixed-age community, others an age-based one. An age range from 55 to over 90 years allows natural renewal to take place,

with younger and more able members providing help for the most disabled. Cohousing has spread from Europe across the Atlantic, taking several new forms.

In **North America** several types of supportive intentional communities have emerged to challenge the isolation and social exclusion that many older people experience. The vast distances of the USA and habits of driving, fast food, material consumption and TV can exacerbate isolation, disconnectedness and fear, argues Wann (2007). His solution, for older people, was a 'neighbourhood on purpose' – where several households collectively buy land and property where they drive less, exercise more, produce their own food, energy, and entertainment, meeting needs for security, self-expression, affectionate friendships, democratic decision-making, shared leisure and mutual respect (ibid). Wann's group of 60 people had been inspired by the lively interactive quality of Denmark's cohousing, as conveyed by McCamant and Durrett (1988). Their book generated a USA cohousing movement, with over 100 communities formed by 2007 and more planned. Cohousing takes several forms including cooperative schemes based on a shared building, with resident control and self-governance, often based on common values - religious, utopian or ecological. Those communities that recruit or breed younger members can adjust to the increasing care needs of older members, remaining age-balanced and resilient. However, older people may find they have less say in decisions in a mixed age community. Senior Cooperatives cater only for older people: 'the fastest growing housing alternative in small town America'.

Among more adventurous older people, mutual assistance is provided in Transient Recreational Vehicle (RV) clubs. These offer a supportive social network and RV parks for temporary settlement between travels. Women in RV communities care for others who are ill or dying.

Canada has had housing cooperatives for some time, some started by older people as retirees needing affordable housing where members would share responsibility for one another. In Toronto a 152-unit cohousing project for women aged over 45 was opened in 1997 by the Older Women's Network Cooperative. It allocates some units for disabled and abused women, providing a safe and affordable home for all.

We have described a variety of forms of cohousing across two continents. They differ in some details but all foster a sense of responsibility for members; an ethos that allows people to thrive in a secure and friendly environment; that both protects and stimulates; that engenders mutual respect and preserves choice and autonomy. A private front door and personal space matters to most people over 50, as do good neighbours and opportunities for easy everyday social interaction. Cohousing can meet these needs, improving the quality of life for older people needing only modest amounts of help and making efficient use of scarce building land. A bonus is the potential for reducing dementia rates by preventing isolation. Less clear is the capacity for coping when members develop conditions such as dementia, stroke or incontinence, although US evidence suggests mixed age groups can cope better. Because there are no senior cohousing communities in the UK, the concept cannot be evaluated here. However studies in several European countries suggest it is beneficial and popular among residents and European schemes provide practical models for such developments in the UK.

j. Some radical alternatives to institutions and staying at home such as hotels, cruise ships

Some older people in the UK used to move to hotels or boarding houses (often by the sea) in old age. Even recently there has been publicity about one or two older people who have moved to an hotel. 'The couple who stopped at a Travelodge – and stayed there for 22 years' (*The*

Times, 11.9.07) and 'Why shouldn't older people choose to live in a Travelodge?' (*Guardian* 11.9.07). They are now said to have moved out. Moving to a little more evidence rather than anecdote a study published in the *Journal of American Geriatrics Society* (Lindquist and Golub, 2004) claimed that living on a cruise ship provides a better quality of life and is cost effective for elderly people who need help to live independently. The author Dr Lee Lindquist compared the amenities and costs in assisted living (in the USA) with accommodation on cruise ships. 'Both cruise ship and assisted living facilities offer single room apartments with a private bathroom, a shower with easy access, some help, cable television, security services and entertainment. Cruise ships, however, have superior health facilities – one or more doctors, nurses available 24 hours a day, defibrillators, equipment for dealing with medical emergencies and the ability to give intravenous fluids and antibiotics' (ibid). In the original article the authors also claim that contact with relatives would be encouraged. As they put it 'go see grandma' would be a good option for children and grandchildren who would get to take a holiday at the same time. (Lindquist and Golub, 2004, p. 1953).

10. Key factors for revolutionising long term care for older people

a. Good design of homes and towns

Homes built to Lifetime standards (already described) are ideal as they can enable someone to live in them for all their lives. To be welcomed is the advice from the Minister (3.1.12) to local councils to consider the needs of older people in their housing plans, by ensuring that new homes being built include features such as wider doors for wheelchairs and walk-in showers. Equally important is the wider environment such as towns that are age friendly (see the work of the WHO, 2007 and Biggs and Tinker, 2007). Planning has a role here too.

b. Changing patterns of informal and formal care

There are at least two aspects of care. The first, and the most important in terms of size, is informal care (see section 4e). Co-resident care, particularly that given by spouses, was noted as crucial in our work for the Royal Commission in 1999 (Tinker et al, 1999). As well as family care, there is care/support from others in the community. A befriending service is quoted in a DH document on mental health (DH, 2011a). Research based on an evaluated pilot under the Brighter Futures Group programmes, shows that 'preventing loneliness could reduce health service use by older people and led to substantial savings' (ibid, p. 10).

The second type of care is formal, provided by a professional such as a nurse or occupational therapist. In the home it is usually referred to as home care. A European research project, the LIVINDIDHOME study, investigated what reforms had been introduced in nine European countries focussing on 2000/2010 (Rostgaard et al., 2011). They defined home care as help with bodily and domestic tasks in the home of the recipient. The aim of the reforms was to fund and deliver: high quality care which meets increasingly diversified and individualised needs; an efficient and effective provision mechanism and cost containment; a stronger user-orientation in the provision of care; an optimal balance between informal and formal care and other resources; finding the best way to attract and retain home workers.

From an English perspective (and this only covered England as other parts of the UK have slightly different arrangements) research revealed the problems of underfunding (Glendinning and Wilde, 2011) and the need for consistent policies to support more people at home for longer, in order to avoid (or at least delay) entry to residential care. However, entitlement to statutory home care or cash in lieu has been increasingly restricted to those with the highest

needs. For low level/preventive services, older people must rely on voluntary organisations. The expansion of personal budgets and direct payments was intended to give people more control over their care services (see section 7) and to stimulate a mixed economy of supply. With targeting of resources on fewer households, a market has developed with older people and their families buying in services from private providers, using personal budgets and direct payments or their own funds. There has been a growth in private (charitable and for profit) providers but this can bring problems of fragmentation and lack of regulation (Glendinning and Wilde, 2011, p. 113).

From a European perspective there are many of the same issues. However the LIVINDHOME research showed that 'Home care services, like long term care services in general, are embedded within the traditions, values and structures of individual states and any convergence between the approaches of different countries is likely to be constrained by these different contexts. Thus the approaches of the countries in this study to reforming home care services differ in their starting points, reform strategies and time frames' (Rostgaard et al., 2011, p. 24). England is among countries with a long history of both long term residential and home care services and has increasingly aimed to encourage a market in the supply and delivery of home care. While home care users can purchase services through personal budgets, mechanisms are needed to ensure service quality; equity, equality and effective workforce strategies need increasing attention.

c. New products including the role of technology

i. General

Technology in its widest sense covers a range of equipment from the oldest such as telephones to the newest i.e. robots. Equipment can help with mobility, sensory problems, motor issues (such as trembling), memory and problems such as the inability to carry out more than one task at a time. We recognise that the Technology Strategy Board are increasingly using the generic, or umbrella, term 'assisted living'. We use a variety of definitions which are specific to particular cases.

Some technology has been developed specifically for older and/or disabled people. Starting with simple alarms which were found in an evaluation in 1984 to be useful but limited (Tinker, 1984) research has burgeoned. However, research has been very small scale. This technology was often called 'disability equipment' or 'equipment for the handicapped' but not only has the term changed but so has the concept. It now includes mainstream technology, such as mobile phones, and more specifically designed products such as wheelchairs. By 2004, when the term 'assistive technology' began to be used, a definition by the World Health Organisation held that it is 'An umbrella term for any device or any term that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which task can be performed' (WHO, 2004, p.10). Since then the specific terms of telemedicine and telecare have increasingly been used (see Tinker 2011 for a fuller discussion). We discuss another aspect of technology, home modifications/aids and adaptations, in section 9d.

ii. Telemedicine

Telemedicine can be described as the delivery of health care at distance. Described by WHO as 'The practice of medical care using interactive audio visual and data communications. This includes the delivery of medical care, diagnosis, consultation and treatment as well as health education and the transfer of medical data' (quoted in Telecare News July 2012). The assumption

is that there is a health professional either at both ends of the communication (such as a nurse communicating with a hospital) or a patient communicating with a remote professional such as a nurse. Devices can include those for measuring weight, blood pressure, blood glucose and oxygen saturation. The largest randomised control trial of telemedicine is the recent Whole System Demonstrator trial, financed by the Department of Health. Subjects were over 6,000 people in Kent, Cornwall and LB Newham with conditions such as diabetes, chronic obstructive pulmonary disease, heart disease and heart failure who had social needs. The trial measured the effect of using remote exchange of data between patients and healthcare professional to inform patients' diagnosis and management. There was: 45% reduction in mortality rates, 20% reduction in emergency admissions and 15% reduction in accidents and emergencies. A later evaluation found lower mortality and emergency admission rates (Steventon et al., 2012). However, one of the authors has advised caution (Dixon, 2012) because the trial included those with low risks, they had extra support, they were only followed up for 1 year and a reduction in emergency admissions does not necessarily mean an improvement in quality of life.

A follow up of those who had declined to enter the trial found that such interventions as telemedicine were often considered a potential major threat to identity and existing services use by respondents. 'Their feelings of uncertainty were not mitigated when the prospects of installation of the trial was discussed at home visits' (Sanders et al., 2012, p. 10). The researchers found it was important for potential recipients to have the opportunity to discuss their expectations and additional concerns about technological aspects of equipment and service changes prior to installation. Additionally these findings suggest the need for closer proximity between innovation design and evaluation, so that critical insights might usefully feed back into design and implementation, ensuing interventions are 'minimally disruptive' for recipients' (ibid, p. 11). A recent systematic review of methodologies for assessing telemedicine concluded that 'Larger and more rigorous controlled studies including standardisation of methodological aspects are recommended to produce evidence of unambiguous telemedicine services on pre defined outcomes' (Ekeland, et al., 2012, p.8). They also added that telemedicine and assessments are complex interventions and also, tellingly, that there is need to engage with stakeholders, including patients.

The need for innovation in the health and care sector is motivated by current and future population ageing, but also by the projected lack of nurses or other health staff to assess and treat a growing number of patients. As a consequence, governments have worked with the health industry to design telehealth (telemedicine) interventions. A series of studies has investigated cost effectiveness of these technologies. A research reviewing 22 studies on home telehealth for individuals with chronic diseases reveals a large uncertainty surrounding the economic outcomes of interventions (Polisena et al. 2010). Even though a large majority of the reviewed studies showed that home telehealth saved costs, the lack of consistency in economic evaluations and heterogeneity of interventions, population and healthcare systems have generated mixed results.

Legal and ethical concerns about telehealth technologies have been raised by the European Group on Ethics in Science and New Technologies (EGE). They indicate potential problems with the pervasiveness of a technology, loss of trust in doctor/patient relationships, threats to privacy and security of personal health data, lack of adequate infrastructure or capacity to understand and manipulate technology. Although few patients expressed concern about privacy, the other drawbacks of telehealth may also apply to telecare and smart (or ambient-assisted) technologies.

iii. Telecare including alarms

Telecare refers to care provided remotely to a person at home and has been described by a leading expert as the continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living (Hands, July 2012). For example, sensors can monitor the security and safety of older people by automatically detecting a problem and notifying emergencies to the appropriate staff. One of the oldest forms of technology is alarms and one of the first evaluations took place in England in 1984 (Tinker, 1984). Alarms are the main type of technology used for telecare in the home (Kubitschke and Cullen, 2010).

An analysis of the English Longitudinal Study of Ageing (ELSA) – a panel study of people aged 50 and over, found that in 2008 just over 2% had a personal alarm and just over 4% had what they called an ‘alerting device’ fitted to their property (Ross and Lloyd, 2012, p. 4). A subsequent policy analysis estimated that there were around 4.2 million potential users, of whom 2.5 million (about 60%) lived alone and could be considered a higher risk (Lloyd, 2012, p. 3). This study also found that around half of all personal alarm users paid for the equipment themselves and the equivalent figure for alerting device users was around 31%. Recommendations of the study included increasing the scale of use of telecare, despite the cost, promoting its use among informal carers, families and professionals, deploying the disability benefits system, building mobile phones into clear policy and involving the NHS (which may have a greater role in leading commissioning and funding in the future).

A study of carers had found advantages of telecare for them. These included reducing stress and worry, improving their sleep, and enabling them to have a life outside caring (Carers UK, 2012). Carers UK urged mainstreaming of technology, so that there would be an automatic check whether technology was appropriate. Growing evidence from older people about the usability of technology shows it must be reliable, efficient, safe and simple (see for example McCreadie and Tinker, 2005). A key requirement is for information.

Practically all countries in Europe provide an alarm system, although the coverage varies among countries. Telecare has grown rapidly in popularity around the globe, seen as cost effective and potentially reducing costs (DH, 2005) as populations age. Public provision, public reimbursement and the promotion of private initiatives to develop equipment and systems have been identified as the main drivers of development of social alarms in European countries. Some barriers have also been identified, namely the variability in perceptions of the role and value of social alarms, lack of public funding or cost subsidy, weak public promotion of social alarms and limited technology infrastructure. Some countries such as the UK and Ireland have developed large private markets for social care alarms, which have led to a high level of implementation. Other countries such as Sweden and Denmark with much greater public social care provision have lower levels of implementation and less market-oriented telecare services for older people.

Responsibility for receiving alarm signals varies across countries in Europe, partly due to traditions and values of care. Countries with historically little public provision and high reliance on informal care (such as Germany or Spain) mainly route alarm signals to families who can respond to the need for assistance. In contrast, countries with a strong tradition of public provision of health and social care services (such as the Nordic countries) route alarms to professional staff.

Evidence on the positive outcomes for older individuals using telecare devices is inconsistent. For instance, Botsis and Hartvigsen reviewed papers on telecare for elderly individuals

suffering from chronic diseases (diabetes, dementia, heart failure, Alzheimer's disease, etc.) and also mobility impairments. They found little evidence at the international level of a straightforward relationship between using telecare technologies and improvement of health outcomes. Nonetheless, some studies reported high user satisfaction among individuals with chronic conditions as long as they had no cognitive impairments. Also, home telecare has been found to improve health outcomes of individuals suffering from diabetes, heart failure and chronic wounds. On the other hand, telecare has been found inappropriate for individuals with severe cognitive impairments or in need of 24 hour care. These users had difficulties in using the equipment and hence failed to monitor their health successfully. The authors point out that a large number of studies have a small sample and the follow-up period is too short to give clear-cut results for user health outcomes. Similarly, a much larger review on home telecare for frail elderly people and patients with chronic conditions conducted by Barlow et al. (2007) found inconsistent effects of automated data transmitting in a number of observational studies. They reviewed papers with randomised controlled trials with samples of 80 or more people using technologies for monitoring, safety and security and information and support. Most of the papers the authors reviewed (98 in total) were from the US or UK and focussed on information and support outcomes and largely based on people with diabetes or heart disease. Studies on vital signs monitoring show mixed results; some studies stress the clinical outcomes for people with chronic conditions, but these findings are absent in a number of trials. Also, whereas some studies show significant positive clinical outcomes from proactive telephone support or case management where individuals have depression, heart disease, diabetes, asthma, COPD and frail older people, a series of other trials indicates no relationship between phone telecare and clinical improvements or quality of life.

Also, Arras and Neveloff-Dubler point out that residential technologies result in 'the extension of medical dominion to the heretofore private sphere of family and friends' (as quoted in Demiris and Hensel, 2009, p. 112). Moreover, telecare technologies might tie individuals to their homes rather than promoting their freedom. The detachment from human contact has negative outcomes as patients feel isolated. Oudshoorn (2012) reflects on the importance of space and care and uses the notion of 'technogeography'. Telecare technologies or devices create a disruption in the traditional exchange of care between individuals. Whereas care has traditionally been thought of as a relationship or exchange between individuals in the same space, telecare technologies redefine and modify physical space. There is then a physical separation between health or social care professionals and the person with care needs. He also points out that users of telecare are responsible for monitoring their own activities, which entails reorganization of their space and the activities at home (Oudshoorn, 2012). Nevertheless, all these technologies may be taken for granted as they are developed and introduced in what Post (2010, p. 272) refers to 'hypercognitive societies' (in Brittain et al., 2010). Other reported problems with telecare technologies, such as lack of ability to use the equipment provided or failure in responding to videoconference calls and reporting data correctly are summarised in Botsis and Hartvigsen (2008). Not surprisingly, these difficulties or challenges in manipulating telecare equipment were found particularly acute among individuals with cognitive impairments.

Telecare 2nd generation

A wider development of sensors and alarms incorporates more elaborate design, including the potential for the user to communicate with a carer. Use of such technology varies widely across European countries, as public provision and funding play an important part in developing or initiating projects using specific technologies. However, a market in care and health

services has been rapidly developing and growing numbers of individuals are using such 2nd generation telecare technologies. Some countries have established programmes aimed at promoting advanced alarms and sensors in the home. **Germany** has recently invested in 'Ageing Related Support Systems for Healthy and Independent Living' (Altersgerechte Assistenzsystemefüreingesundes und unabhängiges Leben). Since 2004, a telecare home service has been fully operational in parts of Germany. A recent project named SOPHIA has several systems and devices such as an age-friendly telephone set, state-of-the-art alarm service technology including advanced sensing and activity monitoring, and video telephony utilising the ordinary television set. SOPHIA (see references – website ICT & Ageing 2012) has been designed to be provided in conjunction with housing organisations and has been already implemented in cities such as Wuppertal, Berlin and Gelsenkirchen. They offer different service packages that adjust to users' needs (basic, security, contact and comfort), all based on round-the-clock services. In **Denmark** advanced telecare has a long tradition but is not yet widespread. Two projects partly financed by the European Union have been launched: PERSONA (Perceptive Spaces Promoting Independent Ageing) and DREAMING (Elderly Friendly Alarm Handling and Monitoring), both intended to prolong the independence of older individuals in their home. In **Sweden** there have been various government programmes aiming at improving the quality of life and independence of their older citizens; for instance, technology for the elderly (Teknik för äldre, 2012) developed Care IP (an alarm unit with GSM backup) and the 'Growing older' (Hjälpmedelinstitutet, 2012) programme with a large list of projects such as 'Housing and IT'. Assistive technologies are free of charge and municipalities are in responsible for the correct functioning. Telecare services in **Spain** (*teleasistencia domiciliaria*) are provided both publicly and privately. The system has been in place since the early 1990s and has expanded greatly since 2006. Each Autonomous Community is in charge of funding and providing telecare services so that the level of provision varies across regions. In **Italy**, telecare is not common but a project currently in place in Rome is the 'Non Piu Soli', which supports people with psychological and medical support as well as meals on wheels. It also provides telehealth monitoring to over 3,000 individuals (Kubitschke and Cullen, 2010). Other projects are the 'Vallid'Argento', a telecare project that covers approximately 250 individuals, and the E-Care project in the province of Bologna and the municipality of Ferrara. Much wider implementation of telecare services has occurred in **France**. Telecare services have been long used for older individuals and development of these services is jointly done with the public and private sector. The various commercial providers have joined the association AFRATA (*Association Française de Téléassistance*). In **the Netherlands** telecare services are little used among individuals aged 65 and over, but public and private initiatives have been developing since 2000 and a series of pilot projects and programmes are now operating. In **Poland**, telecare services are little used and there is little development yet from the public or private services.

iv. Computers and information communications technology

Underpinning all tele-technology concepts is Information Communications Technology (ICT). This can include computers and televisions. Computers have not been designed with an age range in mind although those who are younger will have been more exposed to the digital age which will stand them in good stead in the future. A European study in 2000 (Ekberg, 2002) helpfully divided its sample of 9,600 older people across Europe into: the digitally challenged – those with no experience and no interest in computers; the technologically open-minded – non-users who are keen to learn about technology and/or wish to gain computer skills; the old-age beginners – those with only basic skills using computers less than once a week; the

experienced front-runners – users with advanced computer skills using computers at least once a week. The Sus-IT study found that some older people reveal exceptional tenacity in attempts to remain digitally connected despite age-related obstacles (see references – website Sus-IT).

In the last decade the European Union has had a particular interest in the potential for ICT to enable older adults to age well at home. In its introductory description, the European project 'Senior' states that 'Technologists and policy makers know that Information Communication Technologies (ICT) could dramatically improve the living conditions of older people, and turn ageing from an economic burden into a potentially productive resource' (SENIOR Project, 2008). The European Commission regards ICT as means to help individuals to participate in society and the economy and as an opportunity to 'generate benefits for businesses and for economy and society at large' (COM, 2007, p. 4). However, it acknowledges there are challenges with ICT for older people, whether due to their personal situation, to communicating with health or social care experts and carers or to the technical aspects.

A growing body of reports and academic research point out that technologies have the potential to alleviate care needs, reduce costs, increase autonomy and individuals' quality life, improve individuals' safety and release informal carers from burdensome tasks. New terms such as 'gerontechnology' and 'domotics' have emerged to encompass the area of technological applications for older adults.

Research on the use of technologies for dependent older individuals indicates some positive outcomes, but also some challenges. The advantages that have been reported in recent studies emphasise the potential impact of technologies to improve people's lives or meet the preference of individuals to age in place by reducing the effects of loss of functional abilities. Also, case studies have shown the impact of technologies in increasing the sense of safety and security of older adults in their everyday life (Petersson et al., 2011). Yet less attention is paid to challenges for older people in using technologies. In the necessary debate about the potential of technologies for long-term care, those difficulties must be recognized in order to inform solutions. Technology has been converging and merging with everyday life resulting in 'cyborgism' (Tomas, 1995). This has diffused slowly and unevenly into older age groups, to 'gray the cyborg' (Joyce and Mamo, 2006). Therefore, assistive technologies must adapt to the older individual and not vice versa (Wey, 2004 in Brittain 2010).

v. Smart homes

Technologies have multiple purposes and meet a large variety of needs. Innovations can range from simple devices to complex networks of monitoring and assistive devices. So-called 'smart homes' have a network of sensors and cameras distributed strategically (Demiris and Hensel, 2008). This innovation is also known as 'ambient intelligence technology'. One of the main characteristics of smart homes is the ubiquity of computing. A major concern with such technology is the tendency to treat users as objects (Brittain et al., 2010).

Smart technologies are different from assistive technologies, although they share some characteristics (Tinker et al., 2003). This third generation of telecare technologies is still very undeveloped in Europe and little evidence of its usefulness for older people has been gathered so far.

According to Demiris and Hansel (2009) smart homes employ autonomous technologies, where the user does not need to operate, or be trained to use, technological devices; this is substantially different from stand alone devices such as pressure cuffs, as users must

have some training to use these. Data gathered through sensors not only help to monitor individuals' health conditions but also to ensure a prompt response in case of a crisis or change of physiological or mental capabilities. Thus, early intervention is a result of gathering important biomarkers that might suggest need for an intervention, contributing to preventing ill-health and enhancing individuals' autonomy.

Van Hoof et al. (2011) carried out an assessment of an ambient intelligence device, the UAS-system. This 'consists of more than ten wireless sensors placed in various parts of the home along with a black box containing hardware components located in the living room or meter cupboard' (van Hoof et al., 2011, p. 312). This system is different from telecare technology as individuals do not have to carry any device with them. The sensors installed in the home help detect falls. Qualitative interviews with clients of the provider SZBS (*Stichting Zorgpalet Baarn-Soest*) were conducted prior to installing the technology and again sometime later. A large variety of individuals was selected, although a common characteristic among the selected individuals was the need for 24 hours surveillance. Out of the 18 individuals of the first round, 12 were interviewed in the second round. The other 6 died, were institutionalised or could not participate for other reasons. There are clear advantages of the UAS system in giving users a greater sense of security and safety as their activity is monitored, which can help to protect them in case of a health emergency or the threat of burglary. Another benefit expressed by the users is the 24-hour care provided by the system. Almost all had some emergency response systems such as a neck-worn pendant, wristband or an audio-voice. However, after the introduction of the new ambient technology they stopped using it. Furthermore, privacy issues were not a major concern except for one person in the study. Overall, the results of the UAS technology show positive outcomes for maintaining individuals' independence in their home and avoiding institutionalisation. Familiarisation has been found to be very important to instill confidence and trust in users about ambient intelligence technology. Although some individuals expressed reserves about the installation in their home, the second round of interviews showed more positive responses and overall support of the ambient technology. Some users of the UAS-system had concerns, for example being troubled by the number of false alarms and other sounds but others regarded false alarms as a sign that the system was fully operational.

Another interesting finding from the van Hoof et al. (2011) research study is the conclusion that individuals with cognitive impairments need a different approach when using technologies. This is particularly important as it highlights the difficulties individuals might have to face in their everyday life with other technological devices that might create confusion and fear. Thus, technological literacy is a very important aspect to take into consideration when applying technologies. Similarly, acknowledging extra difficulties that some individuals, especially those who are cognitively impaired, might face is necessary. Whatever the benefits of ambient technologies, they are best seen as complementary to care by humans.

A major problem of assessing smart homes is the lack of comparable results. This is due to the low supply of smart home technologies and the fact that the large majority of projects are still in an experimental phase (Chan et al., 2008). There is very little research on smart homes and very few evaluations of the impact of smart homes on individuals' health and well-being. A review of literature on smart home projects internationally (a total of 21) by Demirir and Hensel (2008) raised some concerns and challenges but none of the projects showed evidence of the impact of these technologies on health outcomes. A number of technological challenges have been distinguished in the literature. Ethical considerations include issues of privacy, informed consent, autonomy, lack of touch and obtrusiveness. The lack of human touch is linked to the use of telecare technologies (Cheek et al., 2005). There are fears that

human interactions might be severely reduced as healthcare professionals are remote. Thus, the subject becomes objectified as the body is reformulated into a series of alarms, figures and graphs. Also, smart homes devices are distributed around the home of the user. These objects or devices (sensors, tv-top-box, etc.) are visible to external individuals (relatives, friends, etc.) and therefore might lead to stigmatization of individuals as frail or vulnerable (Demiris and Hensel, 2009).

Another major challenge related to incorporating technologies in the day to day activities concerns individuals' desires and preferences. The solutions that technologies offer might not be in accordance with individuals' needs or preferences (Demiris, et al., 2008). Efforts must be made to match individuals' needs and available technology in a harmonious and comfortable fashion. A pilot study on attitudes, opinions and preferences of older adults and the use of technologies to age in place found that older adults have very positive attitudes toward the use of technologies because of the perceived benefits on their safety, social interaction and support (Mahmood et al., 2008). Thus, in conclusion, older people's motivations to use technologies as a resource to feel safe and prolong independence are crucial in accepting and using technologies. These differences stem from personal and social circumstances such as health condition(s) or social support possibilities. Moreover, individuals' preferences vary and there is more or less strong opposition towards the use of technology-based assistive devices. Possibilities to use technologies are highly correlated with health and cognitive conditions. Individuals must be familiarised with the technology and sometimes might need to learn how to use it. This might turn into a challenge and produce greater stress on individuals.

Experiences of smart homes or Ambient Assisted Living (AAL) technologies in Europe

Smart homes initiatives are still in an early stage in European countries. The fragmented provision and social care models to provide and pay for smart home technologies remain as barriers for the mainstream development of smart homes in Europe. Nonetheless, several countries have already initiated pilot projects, but no peer-reviewed studies have been published yet.

The sparse and tentative development of smart homes are reflected in **Germany** where some projects such as SerCho or SmartHome Paderborn have introduced smart home technologies but not targeted at older people. On the other hand, OFFIS project is running two apartments equipped with smart technologies designed for older people. More pilot projects can be found such as the Das MedialeHaus or the Smart Living in Hattingen that assists 54 people in areas such as health, safety and security or comfort. The lack of mainstream smart homes might be explained by the lack of systematic funding and regulations regarding who pays what. However, the **Dutch** government has recently started a programme to fund smart home solutions for older people with dementia; *Smartwohneris* is a smart home pilot project for dependent older individuals to help maintain independence at home for as long as possible. In cities across **Germany**, 65 projects have been launched, although results of users' experiences have not been reported yet. Smart technologies in **Denmark** have been developing at a fast pace in the last year, with private providers being much more common than in other countries in Europe. This, together with public investment, has created a dynamic atmosphere for smart home technologies. Various projects such as the Vaer Tryg project, the Projekt tDet Gode Aeldreliv or the Intellicare Innovations Consortium have been created to identify and develop equipment and systems to improve the quality of life and independence of older individuals. **Sweden** has a very similar development of smart homes and assistive technologies. County Councils and Municipalities are in charge of funding and

providing services for individuals with disabilities. Rules of eligibility and funding are decided by County Councils and Municipalities, which leads to a great variety across the country. *SmartBo* is a smart house for people with disabilities such as mobility or cognitive impairments in **Sweden** (see references - website Deafblind international). The aim is to maintain individuals' independence for as long as possible in their home through using ICTs. This study is embedded within the *SmartBo* project, a home-based technology project aimed at older individuals with mobility impairments and cognitive disabilities. By contrast, in **Spain** the implementation of smart technologies is very low, although there are options available. Public provision and funding is not available, which puts barriers to the development and implementation of these technologies. Smart homes and assistive technologies have recently been promoted in **Italy**. Public support has been growing and examples of public funding can be found in the Province of Trento where smart homes are subsidised. Other projects implemented are the *Domus Project* (apartments with smart technologies for older individuals in the province of Arezzo) or the *Progetto Domotica* (a project for the development of smart buildings). **France** has a much larger participation of private providers, local authorities and housing organisations in smart homes and AAL innovation than South Mediterranean countries. However, the implementation is still low and reaches a low number of older individuals. The main pilots in practice are the *HIS* project in Grenoble and a pilot project called *Vill'Age* (MEDeTIC, 2012) in Alsace. *TISSAD* is a French project to monitor and follow-up home patients with chronic diseases or elderly individuals. It aims at preventing falls and decline in health status. But lack of public funding jeopardizes a wider installation of smart home technologies. In **the Netherlands**, contrary to the lack of public involvement in developing telecare services, smart homes and assistive technologies are largely promoted by public authorities. Already in 1994 a model house was built in Eindhoven. Smart homes and assistive technologies in **Poland** have been little developed. Although it is now a partner in the European Programme Ambient Assisted Living Joint Programme, pilot projects and implementation of these technologies for older individuals are practically non-existent.

In the last decade the European Union through the 7th Framework Programme has boosted a wide range of programmes aimed at promoting independent lifestyles through using technologies. The *i2010* initiative document called for Member States to facilitate the uptake of technologies for ageing well at home. Among the projects recently developed are: *ENABLE* (assistive technology aimed at improving quality of life of individuals with mild to moderate dementia), *SOCIABLE* (see references) is a computing programme for ICT assisted cognitive training and social activation targeting individuals who have no cognitive impairments to individuals suffering from mild Alzheimer's disease) or the *Ambient Assisted Living-Joint Programme*: this is an ambient assisted living project aimed at promoting national research activities to build projects for the future long-term care. The funding is national and European. There have been four calls for research proposals with a large number of projects in each call.

d. Services working together

The Department of Health (DH) paper *Interim measures for Patient Experience at the Interfaces between NHS services* (DH, 2012b) says 'Numerous recent studies and external reports, such as the Future Forum King's fund, Nuffield Trust and the Health Select Committee 14th report on social care, have demonstrated there is currently much interest in integration. They have highlighted how fragmented care is a concern for many people in health and social care, especially those who have multiple, chronic conditions and long-term needs who need care from a myriad of NHS and social care services' (DH, 2012b, p. 5).

There has long been a practice (in theory at least) of health and social services providers working together and endless research on how this may be accomplished in different situations and with different groups. A recent systematic review of the effectiveness of inter-professional working for older people living in the community found that, while there is policy commitment to closer working between professionals to improve health and social care the benefits were poorly understood (Trivedi et al., 2012). It did, however, find that more than half reported improved health/functional/clinical and process outcomes while only a few reported favourable carer outcomes.

It is easy to look at current patterns of care and organisations. However this can date many recommendations. The current planned arrangements are an example of this. The abolition of Strategic Health Authorities and Primary Care Trusts and their replacement with Clinical Commissioning Groups (led by GPs) will mean new groupings for social services (and of course housing) to link with. In addition there is the new local authorities' responsibility for Public Health. In addition there will be Health and Wellbeing Boards, Local Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategies. This pattern in late 2012 shows how the policy landscape can change. A co-ordinated approach has been adopted by Torbay where front line teams have been aligned with those in General Practice (Morris, 2012, p. 262).

More helpful probably is to look at the simpler mechanisms. These can be summed up as: joint use of pooled budgets; joint staff appointments; joint committees; merging of departments; merging of organisations; sharing premises; the growth of multidisciplinary teams; dignity champions; single assessment of clients/patients. However, there has been much less attention paid to the need for housing to be brought in to these links (see Tinker, 2012 and section 9).

A geriatrician, Jackie Morris, in 'Integrated care for frail older people 2012: a clinical overview' argues that 'The key components of effective integrated care are shared knowledge, understanding, training and support. Equally important are shared objectives, leadership and governance' (Morris, 2012, p.257). While 'no single element by itself has been shown to be effective, but the strongest predictors of success have been the active involvement of physicians, the use of multidisciplinary care and case management with access to a range of health and social care' (ibid, p. 257). It is important to change the perceptions of services for older people and those working with them. Many professionals working with older people have poor working conditions, low status and little training.

11. The special cases of people with dementia, other forms of cognitive impairment and those who are dying

a. Cognitive decline and dementia

Progressive cognitive disorders are linked to loss of ability to carry out everyday tasks, problems with memory and communications. People are likely to need help with these tasks and to be kept safe i.e. not to wander.

The Department of Health say that the total annual costs of dementia are £17 billion. 41% of this was accommodation, the estimated costs for informal care support and lost employment 36%, social care services 15% and 8% was for healthcare. Numbers with dementia are predicted to rise from 680,000 in 2007 to 1.01 million by 2051. The cost of 'Long term care for older people with cognitive impairment in England could rise from £5.4 billion to £16.7 billion between 2002 and 2031' (DH, 2011b, p. 19).

Diagnosis is key. The All-Party Parliamentary Group on Dementia 'Unlocking diagnosis' in July 2012 quotes earlier evidence from the Department of Health in 2009 showing the benefits of early diagnosis to individuals and families (DH, 2009b). And another study showed the financial benefits of early diagnosis in delaying admission to hospital and to care homes (DH, 2009a).

'Evidence from animal studies, observational research, and randomised trials show that exercise can reduce cognitive decline, and the change in activity need not be great. A Swedish study found that leisure time physical activity at least twice weekly in midlife was associated with a 50% reduction in dementia. Yet in England only 40% of middle aged people have taken 30 minutes of moderate exercise in the previous month. A well conducted meta-analysis also found that smoking is associated with dementia. Evidence that social engagement delays cognitive decline is promising but as yet inconclusive. However, a recent study indicates that delayed retirement may defer the onset of dementia' (Doyle et al., 2009).

When people have dementia research shows that special housing is successful and this has been known for a long time (see Tinker, 1999). Extra care housing where the older person has their own accommodation but meals and 24 hour help is provided can enable them to live a dignified life. In addition technology can help. A review 'Assistive technology as a means of supporting people with dementia' (Bonner & Idris, ed. Porteus, 2012) shows that it can help with reminders and prompts, for safety, reminiscence and entertainment. It can also reduce stress on carers. The publication gives many examples of interventions which look very promising. Among them are ones under the Design Council challenge – 'Living Well with Dementia Technology Innovation Challenge'. These include 'Dementia Dog' which provides companionship but also prompts the owner to do certain things such as take medication. Another was 'Buddi - Band' which is a wristband which enables the person to be located and to call for help. These await evaluation as do a number of other examples.

Technology can have a role for people with dementia. Devices to ensure safety such as turning off dangerous devices such as cookers and monitors by surveillance are useful although there are ethical issues to do with the latter.

b. People who are dying

Care at the end of life is becoming of increasing importance and one which the Government is paying more attention to. In 2008 the National Audit Office (NAO) on end of life care found that the majority of people would prefer not to die in hospital but that there was a lack of alternative provision (NAO, 2008). DH produced *End of Life Care Strategy* which was intended to change the culture and experience of dying (DH, 2008).

A recent study on people who are dying, including those with dementia, showed a clear preference for dying at home. The key role of home care, either to support family care or to provide direct care, would ensure that more patients with advanced non-malignant conditions die at home (Gott, 2004).

Specific advice on End of Life Care in Extra Housing has been produced and this shows how managers and care and support workers in extra care housing can talk about end of life care with residents to ensure that their wishes and preferences are met (Kneale, ed. Henry & Porteus, 2012). The report concluded 'Dying at home is a realistic option for extra care residents if that is their choice. However, achieving this ambition for many individuals requires sensitive discussion, good care and support planning and effective communication between support staff and the individual and their family. It also means working closely with all the professionals and organisations involved in their care and support' (Kneale, ed. Henry

& Porteus, 2012, p. 3). While another study has found that residents may have to move on, especially those who develop dementia (Dutton, 2012) although another study claimed that this was more of a funding issues than a care one (Pannell and Blood, 2011). The value of learning resources for end of life care in extra care settings has shown the value of improving commissioning and care planning and the coordination of care as well as the importance of training for staff (Jones et al., 2011).

12. Legal and ethical issues

a. Legal issues including human rights

There are many influences on social policy including increasingly supranational and global institutions. It is most apparent in the European Union. In 1988 the European Social Charter had a section (4) 'The rights of elderly persons for social protection'. This included rights to remain full members of society and to choose their life styles and lead independent lives in their familiar surroundings for as long as they wish and are able, and the provision of housing suited to their needs and support for adapting it. At the heart of the actions of the European Commission have been anti-discrimination laws. Based on the European Convention on Human Rights, the Human Rights Act in the UK dates from 1998. Nevertheless age discrimination still exists as does elder abuse and mistreatment. How the Human Rights Act can affect policy is shown in recent High Court judgments. For example, Shared Lives are protected so that no-one can be moved from their family home against their wishes, without a Mental Capacity Act assessment. Another example is over Personalisation policies. These, while aiming to enhance choice and control, place onerous legal responsibilities on older people who use a Direct Payment to employ a personal care assistant. These include complying with all the legal obligations of an employer, including dealing correctly with National Insurance contributions and tax matters; also with the employee's rights to sickness, maternity or annual leave and ensuring safe working conditions. Having Direct Payments could also open up new possibilities for financial abuse of the older person.

While the law may provide some help to older people, we argue that many of the issues we have raised such as the need for more training of staff would go a long way to help support the human rights of older people.

b. Ethical issues

This report raises many ethical issues, some of which are beyond the scope of this limited study. One is intergenerational equity. It may be held that we have argued for more resources for older people and in some circumstances this is true. However the tenor of our report is that in the long run money will be saved.

There are specific ethical issues to do with technology. These include consent, data protection and stigma. The International Longevity Centre (ILC) report details ethical issues on increased use of technology in care homes which are equally applicable to care at home (ILC, 2012, see also Tinker, 2011). There are also many ethical issues to do with people with dementia but again these are also relevant to all older people. These issues have been thoroughly examined by the Nuffield Council on Bioethics in *Dementia: Ethical issues* (Nuffield Council, 2009). At the heart of the issue is 'balancing safety with freedom, deciding what is in the best interests of the person with dementia and recognising that the needs of the person with dementia may sometimes conflict with the needs of others'. They have a special section on the use of assistive technologies in which they point to the advantages in promoting a person's

autonomy and wellbeing by enabling them to live more freely and independently for longer. But they also point to 'possible detrimental effects such as the intrusion on privacy, stigma (particularly with reference to tracking devices) and the risk of reduced human contact. There is also the dilemma over whether the person has the capacity to make decision themselves and, if not, the criteria for giving them technology.

13. What can be done?

a. Changing public attitudes

Although it is of course desirable for staff to know about services and practical things like handling people, something more radical is needed. A radical shift in society is needed that no longer sees older people as recipients of care but recognises their great contributions such as to families, neighbours and society. Part of this is bound up with the low status that is connected to services for older people (Cornwell, 2012). Some argue that there is a need for a change in the expectations of what the state should provide (Corry, 2012).

b. Drawing on the strengths of older people themselves

Discussing long term conditions, DH discusses self-care/shared decision making. 'Empowering patients to maximize self-management and choice, through shared decision making and motivational interviewing. This includes ensuring that: (1) patients engage in shared decision making to co-produce a care plan, (2) both patients and their carers have access to the appropriate information about how to manage their condition, (3) patients are active participants in all decisions about their care ('no decision about me without me') and (4) that patients have access to their medical records. This requires a cultural shift for both patients and clinicians, whereby the importance and value of self care and patient education are truly understood and where shared decision making and supported self care are seen as integral elements of LTC management' (DH, 2012a, p, 21).

A relatively new concept is that of 'Living Labs' which can involve of the involvement of people in all stages of a service. For example Jeremy Porteus (Porteus, 2010) has argued the case for this approach with extra care housing. Not only will full engagement with older people and their families offer 'a tailored personal service and creating a smarter and more dynamic customer-to business relationship. In the economic climate, we are operating in, this must make good business sense too' (ibid, p. 1). A previous study on sheltered housing had highlighted that resident satisfaction and well-being increased as a result of effective involvement and led to a greater sense of ownership by residents and staff, job satisfaction had increased and listening to residents feedback had improved services and the planning of future needs. (Hasler et al., 2010). Porteus quotes the European Network of Living Labs as 'A living lab is a real-life test and experimentation environment where users and producers co-create innovations. Living Labs have been characterised by the European Commission as Public-Private-People- Partnerships for user-driven innovations. It says that a 'Living Lab' is involved in four main activities: Co-creation: co-design by users and producers; Exploration: discovering emerging users, behaviours and market opportunities; Experimentation: implementing the scenarios within communities of users; evaluation: assessments of concepts, products and services according to socio-ergonomic, socio- cognitive and socio-economic criteria' (Best and Porteus, 2012, p. 2).

At a basic level, older people make a great and growing contribution financially to the economy and through later working. Many in this generation have been able to save and may have considerable financial resources. A study 'Gold Age Pensioners: Valuing the Socio-economic

contribution of older people in the UK' (WRVS, 2011) produced evidence to support this. Apart from contributions to taxes the research found that older people provided valuable and increasing financial contributions to society including by their considerable spending power (it is estimated that older consumers aged 65 and over spend on average around £100bn p.a (AgeUk quoted in Silcock and Sinclair, 2012, p. 6), the provision of social care to other older people, the added value of their volunteering and their contribution to charity and other donations.

c. Changing policies

i. Looking for leaders

We need leaders/agents of change. Perhaps the new emphasis on Public Health may have an effect. At the top is Public Health England which is a new body which will be established in the DH to set the overall objective for public health. It will be accountable to the Secretary of State for Health. Public mental health has been defined by DH as 'The art and science of promoting wellbeing and equality and preventing mental ill health through population based interventions to reduce risk and promote protective, evidence based interventions to improve physical and mental wellbeing and create flourishing, connected individuals (DH, 2011a, p. 89).

ii. Age discrimination

There has long been advice about not discriminating on the basis of age in health services (see for example the DH 'National Service Framework for Older People') and provisions forbidding age discrimination in the field of employment are already in force (since October 2008). However, from 1 October 2012 the Government will fully implement the ban on age discrimination enshrined in the Equality Act 2010 giving protection against age discrimination in services provided by public, private and third sectors, clubs and associations in the exercise of their public functions. The Equality Act 2010 states that 'chronological age must not be used as a substitute for an individual assessment of a person's needs'.

iii. Improving health

Measures to improve health would keep some people out of institutions. 'Both epidemiological and biological research shows that the pace at which people age (as determined by physiology) can be modified. Many of the actions necessary are those that would form part of any broadly based strategy to promote population health, such as measures to reduce smoking, improve diet and increase physical activity. The resulting healthier lifestyles can slow the processes involved in many common disorders of old age such as ischaemic heart disease' (Doyle et al., 2009).

For many older people an event like a fall can prove catastrophic and be the forerunner to hospitalisation and a steady decline in physical and mental abilities. Measures to prevent such an event are urgently needed. However, prevention is not always an exciting policy when more high profile actions are more appealing. There is plenty of evidence that lead to this being a priority in the future. For example many examples are given in a research paper 'Pathways to prevention' that include hospital discharge schemes that have helped speed up patients' release which have saved social care budgets at least £120 per day, adaptations that can reduce the need for daily visits and reduced or removed the needs for home care (savings range from £1,200 to £29,000 per year) and a rapid responses adaptation scheme that saved the NHS £7.50 for every £1 spent (quoted in Stirling, 2011, p. 5).

Some government initiatives are small scale though well intentioned. For example local authorities have been invited to apply for a total of £20 million for a fund to make the homes of older people warmer (DH, 2009a).

There are many other examples of preventive services such as schemes to prevent hospital admission and readmission and falls prevention services all of which would save money and help older people. It is also important to recognise mental health problems such as depression and dementia.

iv. A higher profile for housing

We have pointed to the neglect of housing and would like to make the case for more attention to be paid to this important service both nationally and locally. There is extensive research which shows that simple measures such as housing adaptations, practical housing related support and re-ablement can play a major role in preventing entry to an institution (e.g. University of Birmingham 2010). One encouraging recent initiative is the setting up of new public health functions in local government. 'From April 2013 local authorities will have a key role in improving the health of their local population, working in partnership with clinical commissioning groups, and others, through health and wellbeing boards in their localities. They will be responsible for commissioning and collaborating on a range of public health services and for advising the commissioners of local NHS services. Health and wellbeing boards are being established by LAs in partnership with NHS clinical commissioning groups and others. The boards will be responsible for preparing comprehensive joint strategy needs assessments and joint health and wellbeing strategies, and will have a role in commissioning plans to take those assessments and strategies properly into account' (DH, 2012c, p. 1). The encouraging thing is that they go on to state the clear link with housing 'These important new responsibilities in local government will join existing roles that substantially influence the health of local people, for example environment, housing, economic development and regeneration, education and care services' (ibid).

There is a strong link between physical long term conditions and psychological distress/disorder (DH, 2012a, p. 23). The latter are much more common than physical problems. People with these conditions are more likely to develop other long term conditions. Untreated depression leads to worse health outcomes and increased health care spending (ibid). Therefore preventing and/or treating mental health problems would be a good investment.

d. Encouraging new providers

With a change in emphasis of the welfare state there is need for a rethink about the respective roles of organisations. With the voluntary sector taking over some roles, such as housing associations from local authorities, the private sector can have a role to play too. This has already happened for extra care housing and a recent study stated that 'Policy makers should recognise and encourage private sector development of extra care housing' (Kneale, 2011, p. 133). There has already been a large expansion of private home care. However, it is important that small providers have acceptable standards. Older people choosing from private providers with more of their own resources such as personal budgets presents a challenge to society in maintaining standards as well as to families. An interesting case for not for profit providers was made by an individual in Hull Telecare who felt that there was a need for a High Street presence of 'not for profit shops with a social conscience'. He maintains that once a device becomes a 'health' or 'care' device companies can 'add a couple of zeros' to the price (Best and Porteus, 2012, p. 11).

e. Changing practice including new ways of doing things

An interesting approach has been recommended for people with mental health problems in a DH (2011b, p. 12) publication which is based on the economic case for policies. It included 'the acute care pathway' which highlights all the steps/interventions that can be taken before

anyone is admitted to an institution. Similarly care pathways and ways of navigating them are one of the means identified for the housing sector in delivering the National Dementia Strategy (Garwood, 2008).

f. Staff - changing attitudes and training

A group of experts have recently claimed that 'The majority of staff providing the physical and emotional care for older people in hospital and at home have few qualifications, are on low pay and have poor working conditions' (Cornwell, 2012, p. 1).

In addition many health professionals were educated and trained for a different era. Ageriatrician writing about staff in all types of employment working with older people has recently said 'Staff recruitment must select for candidates who can demonstrate their ability to deliver humane and compassionate care. Once appointed they require support, understanding and training. Treating them with dignity, kindness and respect will make it easier for them to do the same for their clients' (Morris, 2012, p. 262).

There is need for strong professional and clinical leadership and workforce development to deliver both old and new services. A group of experts have argued that 'The quality of interactions and relationships between frail older people and professional caregivers is shaped by the team and the organisational 'climate' of care. Effective managers and staff working in a supportive organisational context could remedy many of the problems encountered by patients and carers in both their own homes and hospital. Actions can be taken at different levels of the system to deal with this issue, but we believe that the responsibility for quality of care and outcomes for patients is firmly located at the level of the team. The main purpose of decisions and decisions taken at other levels of the system should be to enable frontline staff do their work' (Cornwell, 2012, p. 1). The workforce at all levels needs to be suitably equipped and trained. They 'need to be supported to deliver more personalised care and to understand the culture change needed to support people to understand their condition and to feel more in control. This means changing part of their role from being expert 'fixers' to becoming coaches and enablers' (DH, 2012a, p. 32).

It is important to promote the recruitment, training and retention of workers including recruitment and retention strategies, professionalisation and qualifications and the role of migrant workers (see Rostgaard, 2011, p. 27 for home care workers). A change of role may be necessary. For example home carers in Sweden were originally housewives (many of whom were entering the labour market rather than staying at home) but became more professional (Larsson et al., 2005).

Staffing issues also need to be addressed by professional bodies. The expert group that met in 2011 recommended that 'professional bodies and those bodies responsible for education and training, revalidation and appraisal develop strategies to change their perceptions of older people's services and to create the future workforce that older people need' (Cornwell, 2012, p. 7).

g. Paying for services and products

Although our focus is not on the economic case for a change in long term care we cannot ignore the financial aspects. If services, whether publicly or privately, are provided they have to be paid for. Many people have, of course, paid privately such as for care in a nursing home or private domiciliary care. If the service is good then people will want to use it. We would like to see more encouragement for this. However, for many others they will not have the resources and will need some help from the state. We believe that the electorate would be prepared to pay for a service such as Long Term Care if it is seen to deliver one of high quality. There

are advantages too with a uniform service being delivered that ensures a certain standard. However, the increasing use of money being given directly to the users can have advantages. It enables personal choice rather than a 'one size fits all' approach.

Grants to enable providers to work together are not new. For example pooled budgets have been in existence for many years. They allow local and health authorities to pool their budgets and then make joint decisions about how a service may be provided. Some of the newer grants have potential for allowing the payment for services. Under the last Government 'Total Place: a whole area approach to public services' HM Treasury and the Department of Communities and Local Government (DCLG) in March 2010 announced the results of 13 pilot projects which they claim have demonstrated 'real service improvements and savings to be made' (HM Treasury and DCLG p.5). This was through special grants for specific areas of work including services for older people. But amounts are often small and for pilot projects only. 'Total Place' requires 'the active engagement of Government and all local service delivery bodies. I present a series of commitments that will give greater freedom and flexibility to support a new relationship between Government and places. The features of this new relationship will include: Freedom from central performance and financial controls; freedoms and incentives for local collaboration; Freedom to invest in prevention; and Freedom to drive growth' (ibid, p.5). Budget decisions following this included a loosening of central control such as de-ring fencing of £1.3 billion of local authority grants from 2011 – 2012 and the removal of a number of national indicators. Under the current Government there has been an emphasis on Community Budgets with a similar emphasis on local involvement with Whole Place budgets at a more strategic level and Neighbourhood budgets at a more local level. Both are designed to bring together service providers.

At a personal level there are ways of obtaining services without payment, for example by swapping services. These are called Timebanks. They can be used for individuals who offer a service and bank the time and then use another service in the Timebank. For example an elderly person may offer to baby sit in return for help with 'do it yourself'. Timebanks can be used by organisations who can offer a service and then exchange them for others. DH say that 'Developing social capital through projects that build community capacity can benefit the community at large, as well as individual, recipients and providers involved in such initiatives', (DH, 2011b, p. 8). They also quote some research by Knapp et al. (2007). Separate economic modelling by the LSE found that the cost of each time bank member would average less than £450 per year, but a conservative estimate of the contribution of each member would exceed £1,300 (ibid).

h. Giving more information

Research shows the lack of information which professionals, families and older people have about services. For example research on technology for the home showed a striking lack of knowledge (Wright et al., 2005). Publicity about, for example, Disabled Facilities Grants, might enable more awareness of what can be done.

i. Measuring outcomes and the need for more research

Many of the examples that we originally found had not been evaluated. While descriptions are, of course, valuable, there is need for some kind of evaluation. This does not always have to be a full cost benefit exercise but it does need to go beyond the simple description. The NHS Outcomes Framework will help but there is also need to look more carefully at small local initiatives to see what can be learnt.

j. Using institutional care more creatively for non residents

Residential care homes have many facilities, such as laundry rooms and dining rooms which could be used by people from outside. But a note of caution needs to be made here. Research has shown that this has to be done very carefully for the building is the home to the residents and the presence of people from outside may be resented (Wright, 1995). However if simple steps are adopted such as a separate entrance and the rooms are not necessarily used at the same time as the residents then it can work very well. For example, non-residents can be asked to come in for certain social events.

The ILC 2012 report argues that the care home of the future must become a community hub delivering a range of services under one roof or in closely integrated neighbourhoods. A Welsh study suggested that community hospitals might act as a centre for co-ordination of services and possibly equipment (Warner et al 2003).

k. The role of industry

In the UK there is great potential in the housing market to expand building both for life time homes and for specialist housing such as extra care schemes. In the USA, after a period when the housing market collapsed, demand is now outstripping supply for retirement and assisted living property (New York Times, 3.8.11). There is also great potential for investment in refurbishment (including repairs and adaptations) and in technology products. The large study Sus- IT on IT use has produced helpful information on how to stimulate new product development for the older market in their paper (see references – website Sus-IT).

Investment in pharmacy could also help. For example the School of Pharmacy, University College London (UCL) recommends better use of community pharmacies to educate communities about preventative health and healthy lifestyles (Gill and Taylor, 2012).

As the population ages across the globe there is an expanding worldwide market for housing related technologies that can extend independent living at home. While Japan has been at the forefront of innovation to date, there is a massive potential export market, particularly for adaptations and equipment for homes. More certainty about future policies would help future investment. While changes create opportunities, a long term plan would help stimulate more external investment.

14. Changing institutional care

Research shows that some care homes can be successfully remodelled to become extra care housing (Tinker et al., 2007). While not a cheap option, and not always possible, this is something that should be seriously considered as it gives people more independence and autonomy than a care home.

In a few cases we have found positive evidence following the closure of a care home. For example in Birmingham an evaluation following the closure of some residential care homes and linked day centres and their replacement with new special care centres, new housing services and in other forms of residential care (Glasby, 2011). Birmingham plan to close all 29 residential care homes in the next five years. They plan to develop eight Special Care Centres with half of the beds in each centre providing long-term stay. The centres will also provide intermediate care and rehabilitation. Extra care housing will be expanded, with enhancements made to existing provision and new development schemes undertaken.

Interviews with a sample of the older people after the closures showed that 42% from each setting suggested that life had got better following the resettlement programme, a further 35% suggested life had stayed the same and 19% suggested life had got worse (ibid, p. 4). However, half of the latter suggested that this had been due to deterioration in their health rather than the services of their current care home.

While our focus is on alternatives to institutional care we acknowledge that, for some people, especially where nursing care is needed, it will remain the best option for the point of view of the older person and carers. However, we feel that much could be done to improve this form of care.

15. Next steps including the need for more research

Our evidence comes from evaluations. We strongly suggest that some of the other initiatives we refer to are evaluated. These include some of the very promising ones on technology and dementia listed in the Housing LIN 2012 report (Bonner & Idris, ed. Porteus, 2012). Many reports, including the HAPPI one and that by the National Housing Federation 'On the Pulse' (Leng, 2012) contain fascinating descriptions of schemes but it would be helpful if they were to be fully evaluated. A good example of the benefit of evaluation of projects is that of the test sites commissioned to facilitate the implementation of the National End of Life Care Programme (Jones et al., 2012). It would also help to be able to do more research on the costs of initiatives. For our part we would like to explore in more detail some examples from the Netherlands (a case study) especially of their housing and technology. We also feel that there is more to learn about cohousing. There is little known about the trajectories of older people and how well different settings of housing with care are able to cope with changes in care needs. The extent of unmet need over time and place needs monitoring.

16. Conclusions

Institutional care and aspects of long term home care have persistently been found wanting by older people and their families, although residential options will remain necessary where 24 hour support and help is required. A continuing issue in long term care has been the low status, lack of training and excessive workloads of formal carers, preventing them from giving care in the way that older people would prefer. In particular, research with older people has shown they appreciate kindness and respect as well as practical help. As this report argues, the forms and practices that have become entrenched in long term care must be improved if older people's autonomy, quality of life and identity as individuals with particular histories and hopes are to be maintained.

This report has therefore explored radical alternatives to institutional care that enable older disabled people to take the lead in shaping their own care solutions, breaking with previous long term care patterns. We describe a range of small scale 'housing-with-care' ventures across Europe and North America, developed over the last two decades, that offer attractive choices for older people with care needs in their final years. Many of these schemes operate in a socially inclusive way, maintaining self-hood, even where inputs have to be quite intensive for very frail people. Outside the UK, substantial numbers of older people have experienced new arrangements and mainly reported satisfaction. Financing care for greater numbers of older people has always been a problem but innovations in housing-with-care could reduce costs. For example, Nordic cohousing schemes are very popular, with waiting lists and Homesharing in Australia is evaluated as successful and cost effective. In the UK such

new configurations have not yet become widespread and may still be confined to a property owning 'elite'. Technological innovations are promising, but evaluation shows they need to be much better attuned to older people's preferences and requirements. Innovations such as personal budgets and direct payments have not been received with any enthusiasm by older people; the research indicates that most want more choice and consultation within the Local Authority service provision; moreover cash-for-care is not cost effective in the case of older people. A significant constraint on LA care provision is budget restrictions, limiting the support that social workers can give in planning care, reducing the amount and quality of agency care that can be given to older people, undermining their choices and preferences and, by excluding many from assistance, placing intolerable burdens on informal carers whose own health is thereby compromised.

Underlying our report is a consideration of what is best for older people and their carers. It is argued that many of the issues we have discussed would not only lead to this but also, in many cases, to cost savings. Not only would some people not have to go into institutional care but the emphasis on e.g. prevention and building on the strengths of older people themselves would improve health and well-being.

We have given more weight to some initiatives that seem innovative and underdeveloped. These are extra care housing, home modifications/aids/adaptations, technology and housing in general. All would be prime topics for the Technology Strategy Board and for industry to invest in. In addition the role of some other options such as co-housing and the fundamental plank of informal care (especially co-resident /spouse care) need to be urgently addressed.

In particular we have provided evidence that the Technology Strategy Board through its role in grant giving can contribute added value to stimulate innovation around long term care for population ageing in both private enterprises and statutory sector. Our examples of innovations and promising schemes have come from the statutory, private and not for profit organisations. We also feel that harnessing the strengths of older people themselves, not only in the provision of services but at the start and throughout the research process, would bring about better focused solutions. Older people are resourceful and their expertise should be brought in to both the design of services and research.

We hope that our findings will provide the basis for stakeholder interest, engagement, and support in finding new and innovative ways of addressing cost effectiveness of social care provision, choice and improved quality of life and provide the basis for the next phase of the Technology Strategy Board's investment into developing the programme.

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Methodology

We are a multidisciplinary team covering Gerontology, Social Policy, Anthropology, Political Science, Economics and Sociology with expertise in both quantitative and qualitative methods. Apart from our individual contributions we have jointly brainstormed on the more complex issues. This is based on a vision of 2020 but also 2050 (desk research based on the UK and mainly Europe. Please note that this is not a systematic search of the literature).

We have searched the literature (through both acknowledged data bases such as Ageinfo, Google Scholar, Web of Knowledge) and the grey literature and have had regular team meetings to put together a coherent picture to answer the issues posed above. This has been shared with colleagues both in IoG and other appropriate experts to build on this to revise and improve the findings.

Note

The views expressed in this report are those of the authors and are not necessarily those of the Technology Strategy Board or the HealthTech and Medicines Knowledge Transfer Network, who were the funders of this research, or the Housing Learning and Improvement Network who have kindly agreed to publish this report.

About the Institute of Gerontology, Department of Social Science, Health and Medicine, King's College London

The Institute of Gerontology at King's College London is one of the leading gerontological research and teaching centres world-wide. Founded in 1986, the Institute is at the vanguard of multi-disciplinary research and teaching, acting as a bridge between the social and clinical sciences. The Institute has many long-standing research and teaching collaborations including the Institute of Psychiatry, the School of Medicine, the School of Nursing and Midwifery and the School of Biomedical Sciences.

The objectives of the Institute are to;

- Engage in state of the art research in the demographic, sociological, psychological, financial and institutional processes of ageing.
- Provide multidisciplinary research led education and research training for both clinical and social scientists, including practitioners in health, social care, government and the voluntary sector.
- Engage critically with social policy issues for the benefit of older people both internationally and nationally.

The Institute's interdisciplinary nature is reflected in its broad research sponsorship base; it has received funding from UK Research Councils (i.e. ESRC, MRC, EPSRC and AHRC), from numerous charities concerned with the welfare of older people, and from government (including the Department of Health, the Department of Communities and Local Government and the Department of Work and Pensions). The Institute's recent research has included a study of elder abuse; pensions and poverty; housing and technology; the health and social concerns of 'new' ageing population, end of life care and bereavement; the demography of informal care; and the biology of natural ageing. Current research is focussed on three core areas: (i) ageing policy, health and healthcare; (ii) ageing policy and family life; and (iii) global ageing.

About the Housing LIN

Previously responsible for managing the Department of Health's Extra Care Housing Fund, the Housing Learning and Improvement Network (LIN) is the leading 'learning lab' for a growing network of housing, health and social care professionals in England involved in planning, commissioning, designing, funding, building and managing housing, care and support services for older people and vulnerable adults with long term conditions.

For further information about the Housing LIN's comprehensive list of online resources and shared learning and service improvement networking opportunities, including site visits and network meetings in your region, visit www.housinglin.org.uk

The Housing LIN welcomes contributions on a range of issues pertinent to housing with care for older and vulnerable adults. If there is a subject that you feel should be addressed, please contact us.

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