

**JRF programme paper:**  
A Better Life

# Innovation and better lives for older people with high support needs: International good practice

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This paper:

- identifies innovative ideas and suggestions already in circulation in the UK and globally that would contribute to better lives for older people with support needs;
- suggests improvements to these ideas and suggestions;
- makes conclusions in relation to diversity amongst older people with high support needs, care issues and broader social issues.

**The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its 'A Better Life' programme, to stimulate and inform thinking on alternative approaches to a better life for older people with high support needs.**

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The Joseph Rowntree Foundation has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy-makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of JRF or the Better Life programme.

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# 1. Themes, structure and background assumptions

## Does the revolution start here?

In writing on better lives for older people in the community with high support needs it is worth considering the legendary reply to a traveller finding himself deep in the rural wilds and asking for directions to a nearby hostelry. 'Well,' came the helpful local's reply after due consideration, 'I can give you directions, all right. But if I were you I wouldn't start from here.'

Where is it that we are at the moment in this context, and would we start somewhere else if we could?

The current landscape has many familiar features in terms of issues generally for older people<sup>1</sup> requiring support – but it also has some features unique to itself. We need to bear in mind that the pensionable age population will grow by 3.8 million over the next 25 years and that the number of people over the age of 85 (the groups where support needs are highest) will more than double (ONS, 2009). Over the next 20 years 1.7 million more people in England alone will have a care and support need (HM Government, *Building the National Care Service*, 2010).

Let us begin by defining high support needs as implying physical or mental frailty of a temporary or permanent kind. This runs a gamut from, say, people in need of re-ablement who have suffered a fall and are planning to return home from hospital through to people with chronic illnesses such as hypertension, diabetes and coronary heart disease up to people living with late stage dementia, multiple physical frailties and sensory deficits who have only managed up to this point because they are supported by a devoted spouse.

Shared problems that these individuals are likely to face include:

- A widely dispersed, post-nuclear family unable or unwilling to provide the support, care and social involvement that our great grandparent's generation took for granted.
- Shortfalls in money for services or quality of life - whether from savings and pensions or from benefits and entitlements.
- Local gaps in specialised services to deal with problems – e.g. access to re-ablement services or respite care, with access determined by the 'post code lottery' and ever higher eligibility criteria.
- Similarly patchy opportunities for leisure and social activities – and in real opportunities for involvement in local decision-making.
- A sense of isolation and loneliness, often accompanied by fear of an apparently violent and threatening external world.

- A further sense of marginalisation based on age – being fitted into a neat box: patronised, excluded from popular culture and socially redundant – a burden.

These problems need to be considered in the context of a recession that many economists are cheerfully describing as certain to be the UK's worst in living memory. In terms of the general political landscape, however, there are some causes for optimism:

- Many older people are relatively asset rich, living in houses that have appreciated relentlessly and which retain value despite the credit crunch.
- A proportion of older people are becoming more assertive about their choices, rights and services: this is to some extent reflected in greater involvement in shaping services and improved service options.
- Despite the poor showing for older people's services in the recent pilot study, the Government's personalisation agenda holds out the promise of services tailored by the individual to their needs and circumstances.
- Politicians are showing a real interest in older people. Funding for long term care has never been so intensively discussed. There are dementia strategies tailored to national UK needs. There is an agreed agenda for personalisation and a promise of a still somewhat mysterious - but alluring - National Care Service<sup>2</sup>. Politicians are taking up older age issues because they are aware of the demographics: the issue of funding care for older people as dementia almost doubles within 25 years can no longer be ignored. Crudely, older people vote and young people don't. Despite the increasing impression of empty point scoring and policy made on the hoof in the immediate run up to the election<sup>3</sup> this factor will not go away: the UK can expect a continuing debate that will grow more rational over time.

There has already been real progress in Scotland, where older age issues were crucial to the last election and have remained central to the political agenda.<sup>4</sup> It is clear from Scottish experience that older people can shape debate on the factors that affect them most.<sup>5</sup>

## **What should be taken as read?**

Within this landscape, before any attempt can be made to discuss and delineate new and effective ideas for positive change, a number of features need to be picked out: changes that are either already partially realised or on the immediate horizon. They are factors that need to be built upon, constituting the bedrock for forward movement on better lives.<sup>6</sup> Once noted they can be taken as read, though there may be different perspectives on where momentum is most needed – and in which direction. These factors include:

- A commitment to relieving the plight of the two million older people currently living in poverty in the UK.

- A link to a pensions agenda that recognises and corrects markedly poor relative provision within the UK as compared to Europe.
- A further link to proactive benefits maximisation for older people.
- A White Paper on funding that delivers adequate and sustainable finances for long term care of older people (whether linked or not to the Labour proposed National Care Service). This must be easily comprehensible, based on a fair contribution from society generally and on insurance contributions or specific taxes. It must sustain services of an acceptable quality. If, as proposed by the Law Commission, it is linked to revised and unified legislation and, more especially, a legislative commitment to statutory rights for older people, so much the better.
- A joint commissioning process between health and social care, which takes savings that can be made from current inefficiencies (e.g. the over use of hospital beds for older people with high support needs to manage social and logistical issues rather than health problems) and ploughs these back into support, linked to a clear preventative agenda.<sup>7</sup>
- The adoption of a standard assessment tool for eligibility for services – and comparison of resource allocation with other groups.
- A re-examination of assessment for continuing care and its application to the care of people living with dementia in particular.
- A safety net for people not meeting draconian eligibility criteria for services or excluded by reason of savings and assets, minimally including free and easily accessible advice.
- Restoration of low level and preventative support, incentivised and inspected for councils and health providers.
- Continued work on the management of chronic conditions (Balanda *et al.*, 2010), on pain relief and on better end of life care.<sup>8</sup>
- Implementation of the National Dementia Strategies and a continuous process of evaluation and re-evaluation of their effectiveness
- Collaborative work across national boundaries on innovations for ageing.<sup>9</sup>
- Implementation of the ‘Homes for Life’ and ‘Lifetime Homes, Lifetime Neighbourhoods’ strategy, accommodating the needs of older people in the design of all general needs housing in the future.

## Structure and philosophical assumptions

Taking as read and consolidating the above where it proves possible, this paper will set out to identify:

- the many innovative ideas and suggestions already in circulation within the UK and globally on both a small and large scale that would contribute to better lives if they were more universally adopted;
- improvements to these ideas and linked 'blue sky' ideas and suggestions that the author or other contributors believe would contribute to better lives for older people with high support needs;
- a summary of conclusions.

Ideas identified in this paper were based on research into existing practice, responses to blogs, and discussion and correspondence with individuals and organisations active in the field.

In addition to the assumptions set out above, this paper is based on some broad ethical assumptions:

- that much UK thinking about old age is unnecessarily negative and characterised by an ageism that will be considered as unacceptable in the future as racism is now;
- that our society should, can and will help people to live better in old age;
- that retirement should be an opportunity for positive change, to be celebrated as such;
- that older people must be able to define their future for themselves.

## 2. Joy in the evening: Current good practice

Everyone will get old. We organise... now and hope that the younger generations inherit ... It is like digging a well for them. They don't have to do it in the future.

(Chinese older people in discussion in a South Yorkshire working group, Chau, 2007).

### **Information, advice and support: more help, less red tape**

One of the themes of responses to questionnaires sent to older people and older age professionals was a need for better information, for simplified processes of assessment and for improved access to advice and advocacy when it is needed.

#### ***Advice services***

A good example of developments in advice services to celebrate would be the FirstStop initiative. Funded by the Big Lottery Fund and Communities and Local Government (CLG),<sup>1</sup> FirstStop<sup>2</sup> is innovative in that it pulls together previously competing advisors from the Elderly Accommodation Council,<sup>3</sup> Counsel and Care,<sup>4</sup> Age Concern/Help the Aged<sup>5</sup> and the NHFA<sup>6</sup> (the specialised arm of HSBC banks, set up specifically to offer advice on financing long term care).

Without a great deal of publicity but by thoughtful utilisation of skills and experience developed individually by the partners, the FirstStop advice line has gathered momentum and is now receiving a significantly higher volume of calls than required by its CLG performance targets. The line offers advice on care and housing support as well as more general advice on rights and services available. It is supported by a website, a library of fact sheets and directories of care homes and retirement housing and is an invaluable resource given the widespread lack of awareness about options available to older people. Advice covers simple telephone responses to questions (supplemented by written advice and referral if necessary) through to a more complicated case management approach for people with particularly complex problems. In short, the meshing of the organisations has been a success, simplifying contact routes effectively for older people but retaining the strengths of and achieving synergies between individual organisations, and as such is a blue print for the future, echoed by the welcome merger of Help the Aged and Age Concern in to Age UK.<sup>7</sup>

Alternative sources of advice springing up include Employee Assistance Programmes (EAPs),<sup>8</sup> almost all of which now offer specialised advice on issues affecting older people. Employee Assistance Programmes are designed to offer advice to employees experiencing stress or difficulties at work and at present are available to about 54 per cent of public sector and 37 per cent of the private sector workers of the UK.<sup>9</sup> Because demand for advice is so heavy, EAPs have developed the capacity for specialised advice on older people's issues. Advice is most frequently requested by carers but many schemes also respond to relatives (including older people) directly. BUPA is a leader in the field and offers an Employee Advice Line with a number of specialist older age advisors.<sup>10</sup> Councils

such as Westminster and Hampshire have also developed advice services with Counsel and Care as a specialist partner.

A useful addition to current services would be a 'Gold Standard' book of advice on ageing which could offer advice to people in crisis as a result of hospital admission and the like. This would benefit from strong branding and a clear generalist agenda in that it would then simplify finding help and might also appeal to younger older people, who have proved a very difficult group to reach

### ***Assessment, self-assessment and joint notes***

It is notorious that current assessment processes for older people are unnecessarily complex and repetitive, with information requests irritatingly and sappingly repeated by health, housing and social care providers. Until recently little real progress has been made in this area. However, a number of Councils have experimented with shared information for re-ablement teams and hospital discharge teams in particular. An example would be Kent County Council,<sup>11</sup> which has also pioneered a widely admired and increasingly adopted automated self assessment process, a gateway to direct and individual budgets.

Another good example of overcoming problems with 'joined up working' is the work of Liquidlogic.<sup>12</sup> Their software offers an Integrated Adult System, which facilitates communication between different disciplines e.g. virtual care and support plans being shared across health, care management and domiciliary care teams. Councils recently signed up include Cumbria, Rochdale and Lewisham. It is also integrated with a self assessment system for self directed support, which maintains budgetary information and allows access to a wider support team: these are exciting and long overdue developments.

### ***Befriending, peer support and counselling***

Schemes for befriending are long established but continue to evolve: the UK is admirably strong in this regard. Good examples for people with high support needs would be the increasing political efficacy of Counsel and Care, the quiet effectiveness of Contact the Elderly<sup>13</sup> (dedicated to social visits and sharing tea: the family setting and the fact that visits are arranged at weekends when professional services are often not available is important) and the initiation and advance of support groups run by and for older people, particularly those living with dementia. The Scottish Dementia Working Group<sup>14</sup> is a fine example: gloriously stropky as well as warm and supportive it has international links and genuine political impact. An example of the myriad small but important charities that have proliferated recently is the Lewy Body Society,<sup>15</sup> dedicated to publicising this little known but particularly difficult form of dementia.

The work of Danuta Lipinska<sup>16</sup> and sympathetic fellow travellers also deserves mention: merging the person-centred perspective on dementia recommended by Tom Kitwood with established professional counselling practice, it offers a psychotherapeutic approach to counselling older people living with dementia that both broadens our understanding of the experience of dementia and will help some

individuals to come to terms with their illness. Very little work has previously been done in this field, yet the need for counselling and the reassurance it can bring is very marked.

### ***Black and minority ethnic group support***

Generalisations about older 'BME' groups within the UK look increasingly unhelpful, attempting to cover a wide ethnic, cultural and age diversity, with needs in part dependent on specifically localised circumstances - and innovations arising from local difficulties and local strengths (Patel and Traynor, 2006). There are, of course, some important shared areas of experience: the experience of racism and allied experience of poverty, linked with health inequalities and the need to tackle ethnically specific health issues.<sup>17</sup>

Debate about improving lives has moved on in this context, too. Initially based on a simple fight to ensure that appropriate and adequate services existed in the face of ignorance or prejudice there is now much agonising amongst commissioners about whether services should remain specialised or move towards integration on some unspecifiable principle of equality and cultural unity. Whilst there are now many examples of support groups that are firmly and happily integrated,<sup>18</sup> there are difficulties for some older people.

Some of these difficulties are exacerbated for much older people, the group where support needs tend to be highest. In brief, factors that may make integration problematic include language barriers,<sup>19</sup> religious and cultural barriers, issues centred on attitudes to gender and a simple preference for spending time with people whose memories, pastimes and assumptions fit more easily with one's own. There are clear examples of innovative projects that are by definition to some extent exclusive: The 'Meri Yaadain' project in Bradford, for example, runs language specific programs for increasing awareness of dementia for sub-continental language speakers. The absence of a word for 'dementia' in the main sub continental languages produces a cultural blindness that can result in inappropriate treatment for sufferers (Tribe *et al.*, 2009).<sup>20</sup> Work carried out to tackle this used local radio very effectively, as well as written literature, talks and outreach work. Another example of a necessarily exclusive but inspiring innovative service is provided by work within the Chinese community, where for want of linguistically and culturally appropriate alternatives older people offer services to one another (Chau, 2007).

Good examples of innovative, largely monocultural support organisations that have nonetheless outgrown isolationism include the specialised Sikh day care centre Guru Nanak in Gravesend, which makes the most of its own networks for community support and has also made a point of working across Indo/Pakistani national borders.<sup>21</sup> Extra care housing projects such as Bradley Court in Huddersfield, St. Eugene's Court in Birmingham and Tia Hua Court in Middlesbrough have taken particular care in building environments and services tailored to Afro Caribbean, Irish and Chinese minorities.

Examples of integrated projects abound: exciting examples include the Leicester Age Concern BME Elders Forum, which unites more than 40 groups from the BME

community in a process of engagement, community cohesion and the development of resources,<sup>22</sup> the Haringey centre that unites Greek and Turkish Cypriots, and a slew of uncelebrated centres across London and the UK where multicultural partnerships are a simple fact of life and where people eat one another's food and share one another's cultural events without reservation.

### ***Lesbian, gay, bisexual and transgender support***

Although attitudes to sexuality have evolved considerably in older age support and in older age generally there is still a distance to travel. There are at present no specifically gay residential homes in the UK,<sup>23</sup> for example, and problems remain for people seeking accommodation and for their partners.<sup>24</sup> The experience can be particularly problematic for older people with dementia who grew up in a time of intolerance and legal constraint. The Alzheimer's Society LGBT Support Group has done some excellent work and produces an occasional newsletter with broad community concerns, including befriending, advocacy and support under circumstances of high support needs.<sup>25</sup> Similar (and more local) groups exist under the auspices of Age Concern UK.<sup>26</sup>

### ***Advocacy and advice***

As with befriending, advocacy is not new in itself (though in shorter supply than it should be) but continues to evolve towards innovation and is particularly important for people with high support needs. Good examples of new developments include Welfare Advocates. Further advanced in Scotland<sup>27</sup> than in the rest of the UK, Welfare Advocates are experienced solicitors who can help people make decisions about capacity, living wills and finance.

Elsewhere in the UK, the Alzheimer's Society UK and others are developing a network of Dementia Support Advisors, who will provide advice, support and training in response to the National Dementia Strategy.<sup>28</sup> The role resembles a social care version of the excellent Admiral Nursing initiative, which has pulled together some of the best nurses in the dementia field and given them a license to apply their skills creatively in the community. They have grown exponentially over their 16 year history as the result of well deserved good publicity<sup>29</sup> and are embarking on a program of training and expansion. There are examples nationwide but high profile strengths in Bradford (building on a long tradition of good practice) and in Croydon associated with an extremely good memory clinic – again, a successful model that is reproducing itself.<sup>30</sup>

### ***Broader ethical issues***

The Nuffield Council on Bio Ethics recently produced a wide ranging and thought provoking report on the ethics of dementia management (Nuffield Council on Bioethics, 2009). More radically, Richard Taylor, a retired psychologist living with dementia himself, recently addressed an international audience in Zurich on dementia, Kantian moral imperatives and Chomsky's theory of universality.<sup>31</sup> The need for continued work is immediately and urgently clear. At present policy makers,

professionals and concerned lay people operate on a mixture of half examined views and instinct.

Society needs a well-focussed debate, providing frameworks for practical advice. A good example would be the robust approach the Nuffield report takes to risk management, making clear that people living with dementia have their lives diminished by overly cautious approaches: where insistence on health and safety exists as organisational protection and where it substantially reduces quality of life it should be re-thought in terms of maximising freedom, the report rightly suggests.

## **Practical help**

### ***The LinkAge pilots***

Financed by the Department for Work and Pensions,<sup>32</sup> this series of eight pilots across the UK encouraged local voluntary organisations to liaise with one another, facilitated by Council commissioning. Essentially, agreement was brokered by partners (with commissioning direction and help) to ensure that local organisations concentrated on what they did best, signposting one another for services best provided by another specialist.<sup>33</sup> This prevented duplication, cut costs and improved the efficiency of local advice. It was often startlingly successful in terms of increased local understanding and improved services and should be universally adopted. There were interesting variant strands to the pilots. In Tower Hamlets, for example, LinkAge employed outreach workers, who checked with visitors to projects within the LinkAge framework and with emergency services in order to identify isolated and vulnerable older people, whom they would then visit and offer assistance when it was wanted – which it frequently was. This is an excellent example of practical and innovative peer support.

### ***Extra care***

Though service user satisfaction is frequently high, extra care housing has on the whole promised much and delivered less than expected in terms of its slice of the market. This is perhaps because it was pushed hard by politicians and commissioners who saw it as a cheap alternative to residential care for people with high support needs - without clear evidence on costs. At its messiest there is a real danger of it becoming a de-regulated form of residential care. There are many good examples of innovative work, however. Housing 21<sup>34</sup> has developed specialised resources for people with high support needs that manage to combine resource centre and day care elements. These are known as plazas and typically include restaurants and shops accessible to the local community within the buildings concerned – but with residents' privacy protected by progressive security. Housing 21 also takes a leading role in improving the effectiveness of extra care for people living with dementia and has issued excellent guidelines for palliative care work within a sheltered context.<sup>35</sup>

The Methodist Housing Association provides a splendid example of specialised dementia care at Moor Allerton in Leeds,<sup>36</sup> with notable skills in helping couples where one partner is living with dementia. Hanover Housing overhauled its provision

at Poppyfields<sup>37</sup> and has supported people with very high needs effectively by combining care and support planning with health care input and by having a post specifically to monitor the implementation of these plans, a simple and effective innovation that has real potential.

Extra care housing is popular with some minority groups as a more socially acceptable alternative to residential care. Sonali Gardens<sup>38</sup> and Colliers Gardens<sup>39</sup> have both deservedly won several awards, offering services to the Bangladeshi community and (in part) to the Chinese community respectively.

Kennedy Avenue, managed by Belong in Macclesfield, deserves a mention as an excellent example of innovative design, using elements of Dutch thinking about involvement in activities to create an environment somewhere between traditional extra care housing and residential care, with strong community links.<sup>40</sup>

### ***Retirement villages***

More popular with many correspondents were the new retirement villages (though they have suffered from the recent slump in property values and general uncertainty about the advisability of moving under current circumstances). Denham Garden Village<sup>41</sup> provides an attractive and successful example of a large, well organised retirement community with the advantages of good location, shopping, restaurant and gym facilities linked to medical help and the provision of support when it is required. A particularly inspired touch was the provision of facilities for local medical teams, ensuring quick and easy access for village residents.

St Monica's Trust has followed a similar blueprint in its Sandford Village development near Bristol,<sup>42</sup> and is linked to one of the best residential facilities in the UK for people living with dementia; in common with some European projects it limits car access and encourages the use of bicycles. Both organisations see themselves as providing homes for life and are committed to managing high support needs through intensive support packages.

Finland and the Netherlands have worked variants on the retirement village concept, with mixtures of lease bought and rented accommodation. Good examples are the Finnish Iso Omena<sup>43</sup> complex, which is built around a shopping centre including cinemas, restaurants and a library, with health centres accommodating dentists and physiotherapists. The De Rokade centre in Groningen<sup>44</sup> in the Netherlands manages intensive needs within a large residential home, spreading through satellite sheltered and general needs accommodation to widening circles of need in a city block – independent living with on site care and support linked to a care home – a model sometimes known as ‘close care’. This is perhaps more familiar as a model (with some local/cultural variations) under the name of ‘hub and spoke’ in the UK. However, a more expressive metaphor with greater potential for powering future innovation might be a ‘heart and artery’ model of care, with its suggestion both of organic links and of two-way flow.<sup>45</sup>

Japan has developed an interesting variant on retirement villages with extra care, effectively managing to combine high levels of support with the leisure concept that

sits at the centre of retirement villages. People with high support needs can book themselves onto cruise liners, properly adapted and with support staff on hand. Costs, of course, are high but a number of correspondents groped towards something like this concept when thinking about an ideal future for themselves.<sup>46</sup>

### ***Residential care and community support***

Residential care is specifically outside the brief of this paper since complimentary work is being completed by other aspects of the Better Life program (My Home Life)<sup>47</sup> and because the focus of the paper is people in the community. However, it needs to be firmly stated that good residential care is a part of the community: several correspondents made or implied this point very strongly.<sup>48</sup> Good homes involve residents in local activities and invite in neighbours, relatives, school children and volunteers on a regular basis.<sup>49</sup> They offer advice to relatives through dementia cafes or their equivalent: they increasingly form a part of retirement communities in the UK and elsewhere. Those that are doing so deserve public credit.<sup>50</sup> Many are now also providing outreach services.<sup>51</sup>

There is clear potential for training exchanges between domiciliary workers (with an instilled sense of the right of the individual to privacy in their own residential space) and residential workers (who are able to acquire skills by working under close supervision and observing one another's behaviour, learning to manage difficult interactions by picking between approaches that work best), for example. This should be explored and developed. As European experience shows, multi skilled support teams working in the community are flexible, easier to deal with from the user's perspective and provide a cheaper and friendlier alternative to admission to hospital if health skills can be levered into the mix.

### ***Building specialised housing for older people***

It is clear that the UK needs to think through the building of specialised accommodation for older people, both to maximise its effectiveness in terms of support and in terms of freeing up limited larger housing stock (older people have control over the largest part of the £932 billion of equity tied up in UK homes). It is important in this context to consider space: older people spend more time at home than younger people and have a lifetime's worth of possessions. If they are to consider moving from the large homes in which they have raised families (freeing this accommodation up for younger generations) they must be offered sufficiently spacious alternatives to allow for comfortable living and the room to maintain activities that they have carried out through their lives. There may need to be bedrooms for family visitors or live in carers – Australia has done some interesting work on matching people with high support needs and potential live in carers.<sup>52</sup> It would be appropriate to provide this in energy efficient environments, ideally with some room for gardening activities on small plots, in communal areas or on balconies.

Older people will want homes in neighbourhoods that facilitate access to amenities, offer security and peace of mind, space for family visits, light and airy rooms, and minimised trip hazards like difficult-to-reach shelving or steps. One in four falls

involve stairs and the majority take place at home. The HAPPI report on housing and innovation (Barac and Park, 2009) suggests that local planning authorities need to actively encourage movement in this direction, which can be achieved as the result of conversion of office style buildings as much as through purpose building, as at the converted embroidery factory of Solinsieme in Switzerland (Barac and Park, 2009). A good example of a UK based project in this mould is Darwin Court in Southwark, which integrates healthy living through the availability of a pool, café, IT suite and fitness and activity rooms. A sense of integration into the community is achieved by opening these facilities to all local residents (Barac and Park, 2009, pp 14).

### ***Floating support***

Floating support is in essence the transposition of the support services that tenants would expect to receive in sheltered housing to private properties of all kinds. Its disadvantage is that the move towards it deprives existing and potential sheltered housing tenants of a day-to-day relationship with a scheme manager and reduces perceived security, which many feel strongly fails to provide adequate support and so is counter-productive and unjust. However, research indicates some evidence of advantages, too: floating support services have a problem/solution focus that a significant proportion of service users like. This is partly because it is time limited, activated only when necessary and relatively inexpensive (King *et al.*, 2009).<sup>53</sup>

### ***Financing care at home***

Many correspondents implied that equity release is an option they would be interested in looking at seriously in older age. The Joseph Rowntree Foundation is the most reputable of several organisations looking at equity release schemes for older people. The trick in this context is to free up money frozen in privately owned housing without losing benefits, to improve quality of life: adaptations, increased care or support hours or paying for a holiday break are all examples quoted regularly by people with high support needs. The Joseph Rowntree Foundation approach has been particularly successful as a result of involving local councils,<sup>54</sup> who can agree to signpost the service, arrange with locally commissioned services to signpost and ensure advice is available (Terry and Gibson, 2010).

### ***Cohousing and housing co-operatives***

‘Cohousing’ is a concept based on bringing together individuals and families in communities of shared interests, whilst allowing people to enjoy their own self contained accommodation and personal space. The idea originated in Europe (and is very successful in Norway, Denmark (where it has its beginnings) and the Netherlands in particular) but has also spread globally, with a flourishing movement in the US.<sup>55</sup>

Cohousing is based on the principles that:

- communities are set up and run by their members for their mutual benefit;
- members have chosen to live as a community;

- developments are designed to encourage social contact and to foster a sense of neighbourhood among members;
- there is a commitment to sharing amenities (laundries and workrooms, for example) and to democratic community management, which often also extends to occasional communal meals;
- the community involves itself in the design of its buildings and social spaces, thinking through the implications of its commitments to shared facilities and communal life.

Cohousing is sometimes simply described as recreating friendly neighbourhoods, or as creating 'intentional neighbourhoods'. Participants tend to stress that it involves groups of people working together to solve housing problems for themselves, with the help of partners where necessary.<sup>56</sup>

The cohousing movement holds an obvious appeal to older people: groups can get together to offer one another support on either an age exclusive or a more integrated basis. In practice this tends to be younger older people, thinking through what they would like for their older age: a supportive community of like-minded people, a sociable neighbourhood but the retention of one's own front door. Communities tend to be pedestrianised and to be low energy users as the result of sharing facilities, which also has its own appeal. Whilst some cohousing projects have very definite identities (e.g. specifically gay older age communities in the Netherlands) many are formed by people who have nothing more in common than the desire to solve their own problems and to rediscover a sense of community.

Cohousing projects are increasingly the focus of government attention in the UK, partly because there is some evidence from Europe and the US that cohousing communities provide support to older members that reduces or even precludes the need for expensive institutional care. There are some difficulties intrinsic to the UK: for example, suitable sites are difficult to find – although it is worth noting that a factory has been successfully converted in Switzerland (Barac and Park, 2009) and that Norway regularly encourages the establishment of cohousing projects in areas with high levels of social problems because of their proven positive effect on neighbourhoods.

There are also some issues with UK housing models, particularly if cohousing communities wish to provide some accommodation on a rental basis. However, there are signs that the Government may pass facilitative legislation and that co-operative models of ownership may be attractive investments for pension funds. Housing associations make obvious partners (cohousing projects in this instance are effectively organisations for insisting that housing associations genuinely consult service users before they begin building) but there are some tensions with the paternalism of the model: however, Hanover Housing is establishing itself as a pioneer in the field.<sup>57</sup>

Many older people are entering into or considering cohousing alliances, building communities together for mutual support. Nás na Riogh Housing Association Ltd<sup>58</sup> in Ireland is a not-for-profit organisation for professionals, where 53 units are organised around a campus and chapel for shared activities and lifelong learning projects.

There is an arts centre, a proposed health centre, a space for gardening and links to a primary school for intergenerational activities. The arts centre is crucial, providing the common interest for the community. The project is driven enthusiastically by its founder and owes much to the Irish Council for Social Housing, which has helped facilitate it over a lengthy period of gestation. European models include Herfa til Evigheden ('From Here to Eternity'), begun in Roskilde, Denmark, in 2004. This has been put together by younger older people, mostly still working, as a group of affordable bungalows gathered around a 'common house'. The plan is to evolve as a like minded community towards old age and higher support needs, focusing on mutual support and common interests. The group explicitly see the community as a protection against loneliness in older age.

Many larger European developments have links to other services. In Finland, for example, day centres have well thought through priorities and clear therapeutic goals.<sup>59</sup> They are usually sited near to sheltered housing. This housing is built to impeccable standards. In Sweden this includes large cellars for residents' storage space, for example,<sup>60</sup> often working in tandem with residential units, which (as in the best examples in the UK, where there are so far eight established cohousing projects) are clearly a part of the community themselves.

The cohousing movement is a really exciting innovation, with a great deal of potential, for older people with high support needs and more generally. The general tendency is for such co-operatives to be pre planned by younger old people, thinking ahead, like the Older Women's Cohousing group in the UK: there would be clear benefits to far greater publicity for the concept and for facilitation by local planners.

The broader issue of key communities is discussed later in this paper in the context of social relationships but is an important supplement to co-operative housing generally.

### ***Assistive technology***

Current areas of strength for assistive technology are well known but progress continues to be made with telecare: a good example is the work being carried out in the rural area of Bute,<sup>61</sup> where there is successful remote management of chronic obstructive pulmonary disease, heart failure and diabetes. Innovative work is also being carried out by Tunstall and the University of Stirling<sup>62</sup> amongst others: much work is being focussed on building IT solutions into mobile phones: for example, satellite location and alerts to help manage risk for people who sometimes get lost when they leave home, or adaptation of mobile phones to monitor activities of daily living.

Work is being done by the New Dynamics of Ageing<sup>63</sup> group on similar areas. Intriguingly, they are also working on smart clothing and wearable technology: this includes experiments with clothing that supports older people with muscle wastage, maximises heat retention and minimises incontinence problems. Work is also being done by this group investigating why significant numbers of older people are uncomfortable with new technologies: mobile phones are an example of potentially helpful technologies to which many older people have not yet adjusted.

Interesting work on design and assistive technology has been carried out by the KT Equal group<sup>64</sup>, who have devised computer models to help designers and manufacturers to tailor items such as chairs, kitchen utensils and assorted aids to the needs of older people. The software that facilitates this is now available to commercial designers on request. The group is also associated with Devices for Dignity<sup>65</sup>, a co-operative set up to foster joint work between clinicians, researchers and manufacturers. In a similar vein and an important area for many people with high support needs, Loughborough University are working on a project to make kitchens more age friendly.<sup>66</sup>

Excellent work is being carried out by Professor Geoff Fernie, Vice President of Research at Toronto Rehabilitation Institute in Canada. His assistive technology backed research into mobility issues has produced portable, easily assembled and recycled aids and adaptations including Sturdigrip, a safety support pole operating by compression that can be fitted cheaply anywhere and Toilevator, a package for raising toilet seats.<sup>67</sup> He has also produced the Sole Sensor, a simple device for inserting into shoes, which helps with balance – with a significant prevention rate for expensive and often life-threatening falls.

## **Social environment**

### ***Shaping services***

A number of councils, often with encouragement from active pressure groups, have begun to make a conscious effort to allow services to be shaped by older people. Good examples of this are provided by Hertfordshire,<sup>68</sup> who have made a conscious effort to interact with the older community and to provide transport, education and leisure facilities shaped by a continuous process of dialogue. A similar process has taken place in Manchester based on the Valuing Older People group, with initiatives including work on age friendly neighbourhoods, initiatives for continuing education and tackling loneliness.<sup>69</sup>

A beacon example of mobilisation of power and consequent positive change in terms of resources, facilities and changed perceptions is provided by the extent to which organised pressure groups for people with disabilities have affected the physical, political and perceptual landscape over the last 30 years. Groups like the Greater London Pensioners Forum and the Scottish Dementia Working Group are making big strides in the same direction: there are many less feted groups across the UK following suit.<sup>70</sup> The political challenge for older people with high support needs is to learn lessons<sup>71</sup> and ensure that their impact is as real as that of disability pressure groups.<sup>72</sup>

### ***Shaping the street***

Stirling University have picked up on work taking place globally, experimenting with street furniture and signage in terms of its effectiveness for people living with dementia. Clear and simple signage has been designed and tested with older people using simulations of street environments.

Equally importantly and effectively, the Elders Council of Newcastle<sup>73</sup> have taken a much lower tech approach to making life easier for older people, producing maps that show the locations of loos and benches, important landmarks and journey breakers for many older people with high support needs. A useful extension of this work would be a central government insistence that all councils produce an electronic map of their districts, noting age friendly routes, popular destinations and facilities: this should be publicised on council websites and be legally required to be displayed in all residential homes, sheltered housing and on Council websites.<sup>74</sup>

### ***Shaping transport and disability friendly travel***

A common theme amongst correspondents (particularly older correspondents) was a desire for mobility in older age. To be limited to one's house or to a single room is too close to imprisonment (sometimes solitary confinement) for comfort. The AUNT SUE group (Accessibility and User Needs in Transport for Sustainable Urban Environments) has worked across London and in Hertfordshire to look at areas like journey planners for people with high support needs and the adaptation of public transport to maximise age and disability friendliness.<sup>75</sup> More Councils need to explore this, and work needs to be done on transport in rural areas in particular, where reduction in provision of public transport generally and specialised transport services for people with high support needs in particular has had a pernicious impact. There are also broader issues to note: as one correspondent pointed out, though his own home is perfectly adapted to disability he finds it impossible to visit many friends and difficult to access many public facilities and events. Aids need to be improved and disability friendly design needs to be universal.

An interesting private sector model for supporting people with high support needs has been developed in Japan, where individuals can summon private cab firms through the use of a personal alarm if they feel unwell: the cab firm is equipped with a monitor that flashes up their medical records to the nearest cab driver, who will intervene as appropriate.<sup>76</sup>

### **End of life**

#### ***Shaping our end: palliative care***

The Department of Health/NHS End of Life Care Strategy<sup>77</sup> pulled together best practice in the field of end of life and palliative care. The strategy endeavoured to set and propagate high standards, such as the Gold Standards Framework, together with appropriate training. In a society notoriously uncomfortable with discussion of death and dying this was necessary and innovative work. It pulled together ideas taken from the hospice movement (Worpole, 2009)<sup>78</sup> and Marie Curie Cancer Care practice. The strategy took into account the sobering thought that 58 per cent of us currently die in hospitals (though most of us expressly do not want to) and that more than 50 per cent of complaints about hospital care relate to death and dying (Worpole, 2009). Topics covered included better information, work with families, pain relief, better training, spiritual care and more informed choices about our end based on the Liverpool Care Pathway,<sup>79</sup> essentially a variant on a care plan specific to

terminal care. This work has had a noticeable positive impact on practice and on the zeitgeist generally, reflected in the continuing growth – and higher profile – of the hospice movement.

### ***Shaping our end: assisted suicide***

A significant proportion of correspondents made the suggestion that they would like to be able to choose their own ends *in extremis*. Martin Amis recently made the innovative suggestion of suicide booths on street corners, to be made more palatable by a martini and a medal. There is surely a case to be made here for slow euthanasia, to operate on similar principles to slow food: the Government should be encouraged to make tobacco and alcohol tax free for people over the age of 55 and possession of all streets drugs legal for older people with high support needs. This would allow people to take their own lives at a measured pace, more suitable to a civilised society – and more enjoyably for the participants. Medals could be awarded for herculean feats of consumption, endurance and abandonment, measured against the Richter Scale.

### 3. Building on current innovation: Conclusions and thoughts

#### The real world: diversity, weakness and strength

Older people with high support needs – and older people generally – are not a homogeneous group. Stereotypes are pernicious and fail to take into account that:

- Older people range across a broad age span: from 'getting oldies' at 55 to the steeply rising numbers of people over 100 years old, encompassing low to high support needs across this sweep. It is unrealistic and unhelpful to expect identical interests across this spectrum.
- Older people in the UK are diverse in ethnic origin and upbringing and often have widely different expectations of ageing. Differences of income, family background and culture in its broadest possible sense have similar impacts: differences between rural living and urban life are hardly less important.
- Baby boomers experience versions of the same problems that have beset previous generations. We have collectively assumed that the 'baby boomer' generation will not go quietly into older age. We look for them to 'expect services to reflect their needs and make a fuss if they do not. In particular we expect them to refuse the post-poor house/poor law, be-grateful-for-what-you're-offered attitudes deemed to have characterised the generation that lived as adults through the privations of the war and the 50s.

It is already clear that this last point is only partially true. Age slows most of us down. Resource poverty and physical frailty slow many down further. It is, in the end, less easy to man the barricades at 100 than it was at 20, particularly if your support needs are high. A proportion of the baby boomers, characteristically, will fight for change – but they cannot be expected to win all our battles for us. This is a form of stereotyping in itself and needs correcting: an innovation that older people are increasingly insisting upon is recognition of their own diversity.

#### Care issues: resisting the 'care crunch'

Phil Hope, the last Labour Care Minister, said before his demise that he was much more preoccupied by the 'care crunch' than the credit crunch.<sup>1</sup> It is not difficult to see what he means, despite the recent financial cutbacks. The past 30 years has seen enormous gains in terms of support for older people with high needs - but it has also seen losses. Low level and preventative care, for example, is reduced to a nubbin. There has been a continuous rhetoric of innovation in the care of older people<sup>2</sup> but the reality is meanly allocated domiciliary care scraped out to the thinnest minute, residential care that few look forward to and neglectful and abusive hospitals. A nightmare future is that the personalisation agenda is forcibly linked to a sweeping programme of economic cutbacks and results only in further service cuts, ratcheting up of eligibility levels and widespread loneliness and misery. There is, after all, something odd about the claim that a bespoke service, tailored to individual need,

will be cheaper than a one-size-fits-all package.<sup>3</sup> Perhaps there is no cavalry of cheap, willing labour preparing to charge over the personalisation hill. What can older people and those working for their interests do under these circumstances?

Clearly, resources are a major issue. There is a complex issue here: the needs of older people and of people with high support needs to be balanced against the broader needs of society. Beyond saying that the balance needs a healthy shove in the direction of the vulnerable and that the cross party governmental rhetoric of choice in older age needs to be balanced against an assertion of rights<sup>4</sup> this paper needs to concern itself with its theme of better life and innovation.

Immediately and practically,<sup>5</sup> a priority for real change must be to capitalise upon equity release schemes, with the relatively wealthy old taking responsibility for elements of their own care. We need to think through pooled risk for older people, using elements from Dutch/Scandinavian insurance models, linked to a rational and transparent tax system, which can answer present and future need on the basis of an electorally agreed social compact for older age. This is not wild optimism. It is a process in which we all have a stake – we all expect to grow old; we all worry about our future needs.

This must link to integrated models of care for older people. We need to prevent wasteful and inappropriate occupancy of hospital beds as the result of social problems.<sup>6</sup> We need to use the capacity for innovation described above to pilot schemes that target those who using most resources, reducing costs and improving experience and outcomes. The examples of cross disciplinary teamwork in Kent and the shared case notes available from Liquidlogic should be basic building blocks.<sup>7</sup> We should also aspire to care training that marries the best of basic nursing and social care skills, as in Finland, and training for doctors that bases GPs with older people and encourages integrated solutions, as in the Netherlands. Multi skilled teams are a basis for reductions in hospital admissions, and better lives.

Whilst working on this reduction we need to retain options: day care, traditional sheltered housing and residential care are under swingeing attack, with governmental pressure for savings dressed up as modernisation. These services should be improved not abandoned: they are facilities that older people with high support needs rely upon.

There is firm cross party commitment to the personalisation agenda, with which these services should run in tandem. Problems for older people revealed by the recent pilot study notwithstanding, greater control of resources and of service delivery is both attractive and innately innovative. Using older people themselves to deliver services should be explored. The young old are an obvious choice - but there are exciting opportunities for employment of people with high support needs in peer support and advice.<sup>8</sup> On-line technology opens up employment in this (and other) areas, such as manning advice or emergency call centres – any job that can be managed virtually, requiring experience, empathy and a level head rather than physical strength. More ambitiously, let us look at a virtual Care Manager with high support needs. Who is better qualified to offer advice on options, broker packages or act as advocate?

There has been too little innovative exploration in the UK of private sector involvement in the delivery of personalised services. Potentially useful organisations in this context might be those supermarkets that are keen to develop social capital, that want to broaden their relationship with customers on a cradle-to-grave basis and those that already make a point of employing people over pensionable age (Marks and Spencer, for example). Advantages to older people would include accessibility of services, the high visibility of the provider, the normalisation of need and greater efficiency; advantages to supermarkets would be a higher profile for their brand, recognition of their social importance and an increase in business. Supermarkets could:

- ensure that a welfare check is made when groceries ordered on line are delivered, and referrals-on made when necessary;
- sell services needed by older people with high support needs through a 'safe site', guaranteeing quality, safety from fraud and money back if service users are not satisfied: older people tend not to trust the internet *per se* but are used to thinking well of supermarkets;<sup>9</sup>
- develop call centres set up to respond to calls about equity release, with signposting to home care and repair services, etc;
- develop expertise in care and support package management through call centres, offering discounted, off the peg packages (in partnership with recognised care agencies, with guarantees of quality), tailoring these where appropriate and possible.

## **The revolution will be televised: high support needs and broader social issues**

Helping people to live better in old age – that will be the future.  
(Melinda Phillips, Chief Executive of Housing 21, Guardian Conference, Older People and Ageing Britain, December 2009).

Few passionate observers would disagree with the ideas expressed by Melinda Phillips, a notably energetic and effective fighter for improved housing options for older people. But what resources can be mobilised efficiently and effectively for better lives and social change?

An area of massive potential relatively untapped in this country is organised voluntary work for older people. Younger older people are a large potential labour pool, more numerous and much fitter than they used to be. It is clear that volunteering can provide a sense of purpose and satisfaction missing from many retired people's lives. In the Netherlands, for example, it is a commonplace for people who have retired from work in social care to retain links with the workplace, showing around visitors, working with new staff and service users and continuing to contribute to developmental discussion and social life.

Some older people see this as little better than exploitation, however. Does volunteering have to remain in the world of philanthropy? In a world of pressurised resources this needs to be given thought. We could arguably restore much missed

low level help for people with high support needs by establishing a bankable barter system where younger, fitter older people visit people with higher support needs for set periods of time over a week. They would bank hours, reimbursed at a later date from others who have stepped into the system, with the same motivation and expectations. ('Since the completion of this report Professor Heinz Wolf has proposed a similar scheme: see The Guardian, Society, 08.09.10, Interview section (p5).)

There is, of course, a large band of unpaid volunteers in this country: those many individuals who work as carers for friends and relatives: their position is outside the brief of this paper. The issue of family support for people with high support needs is the unmentionable elephant in the room, however. It haunts many correspondent's responses to questions asked for this paper but surfaces overtly only in replies from people with experiences of other cultures, where the relatively recent British cultural shift from regarding support as largely a family matter is seen as a major social calamity. This collapse is seen as isolating and stigmatising older people, diminishing the family overall through a dissolution of a bond of reciprocity and through loss of intergenerational interaction: a loss of shape based on love and respect.<sup>10</sup> Whatever one's views on this complex and emotive subject it is clear that isolation has increased as a result of this break: loneliness is a pervasive problem of older age<sup>11</sup> in this county and a major worry for most correspondents.

Given these circumstances, older people and British society nonetheless contribute to and value neighbourliness. They value grandparenthood, propping up child care arrangements and re-appropriating a family role. More innovatively, older people are setting about establishing artificial families of their own. Housing co-operatives, in which like minded older people can gather together in 'communities of interest',<sup>12</sup> offering each other companionship and support are growing, and are sure to continue growing, as with Nás na Riogh Housing Association, described above. Downsizing from a large home to a co-operative is likely to prove more attractive as pressure grows on resources to support older people. But physically moving may not be the only option: there are examples of informal collectives where people have made a conscious decision to look after one another to a greater or lesser extent. The 'key community' concept will gain momentum, particularly if it is consciously encouraged in lifetime neighbourhoods.<sup>13</sup> As pressure on resources increases and numbers of older people with high support needs increase some of us will band together and take solace and companionship from the act.

As mentioned earlier in this paper, many correspondents identified a need for information as paramount in terms of better lives (and of better care). Two areas for improvement surface particularly: the need to be able to identify contacts and the need for advice that gives recommendations. Virtually merging information-giving organisations (as for FirstStop, described above) would eliminate the first problem. In an ideal world one portal would allow call centre staff equipped with knowledge about one another's organisations. This portal would tackle calls from all older people with high support needs, or refer on to the appropriate centre. As with the LinkAge model, this arrangement would formally agree avoidance of duplication of services where this is possible.

The second issue, that of wanting recommendation rather than advice, is more difficult – but there is a case for employing volunteer older people themselves, with a specific organisational brief to offer opinions - garnished with disclaimers if necessary.

There is a need to develop more sophisticated information networks amongst older people. Already some older people's activist groups are in contact with one another across international boundaries including the UK, the US and Europe (for example, the Scottish Dementia Working Group, as above). The more this trend grows the more practical help and political awareness will spread and reproduce<sup>14</sup> ensuring that all older people in the UK are online should be seen as a necessity in this context: to equip older people with so powerful a tool for work, play, companionship and engagement with the world must be sacrosanct. It is a national scandal that less than 30 per cent of older people in the UK have ever been on line. It is good to see a work stream from New Dynamics of Ageing, which has specifically set itself the task of overcoming barriers to older people perceiving the internet as the powerful friend it is – if no substitute for a living, breathing social life.

From a market perspective, the power of older people is growing. SAGA's development has shown this potential. The rise of 'The Oldie' has been less meteoric, if nonetheless positive and entertaining. Why, then is the portrayal of older people by the media so negative and disempowering? It is astonishing, for example, that broadsheet newspapers continue to pander to the young, who show no interest in reading them, whilst ignoring or patronising older people, who prop them up.

Clearly, mass media will have to learn to adapt: Otherwise older people will vote with their feet and their purchasing power. The potential exists to capitalise upon this disenfranchised and disenchanting capacity and to develop a satellite TV channel aimed directly at older people in the UK. Sponsorship could come from companies marketing specifically to older people (like SAGA, insurance companies and equity release firms) as well as from a broad mass of mainstream companies, interested supermarkets and from government wanting to manage messages to older people.<sup>15</sup> The audience is, in part, ready made: older people in residential care or confined by high support needs often rely heavily on TV and radio as sources of entertainment, information and surrogate companionship. Content should be interactive and could range from the (still ubiquitously requested) bingo to advice programs on benefits and care and personalisation options available or programming helping people to master using the internet. Less worthily, there is a mass of cheap archive material of specific appeal to older people: homeopathic doses are currently spread across a number of channels – but bringing it together would help to establish a channel that older people felt at home with, and the potential exists for saleable innovation.<sup>16</sup> There is no need for such a channel to be relentlessly bland. The channel would be likely to develop a lobbying role and to function as a focus for crystallising political issues with both a large and small 'p' – raising the possibility of forcing politicians into rational debate on the issues really important to older people on one hand and beginning a critique of ageism<sup>17</sup> and a deconstruction of some of the more relentlessly idiotic and unhelpful attitudes to dementia on the other.<sup>18</sup>

And about time, too. One of the reprehensible failures of the (largely admirable) UK older age representative groups has been their inability to get joint political lobbying sorted out as effectively as it might be. Pressure groups would work more effectively if they shared information and co-ordinated lobbying campaigns. Hence, in part, the inanity of current political debate. Age UK could profitably move into this area, organising lobbying and working towards something concrete: a Question Time devoted to older age issues would be a good start.<sup>19</sup>

Many of the factors examined above are coming into play whether we like them or not. Older people with and without high support needs will be relying on one another more and developing a critique of what is offered to them as resources come under pressure. They will become a more unified and powerful political lobbying group as a result. The demographic time bomb and the credit crunch are, in this sense, as much opportunities as threats providing older people learn to think innovatively – and perhaps to think about older age and high support needs whilst still relatively young and fit.

Thinking creatively about opportunities offered by on line communication and use of mass media, seizing every chance to fight back against exclusion by rejecting ageism and making the most of the developing political situation's possibilities for positive change should be the task of all of us. More importantly we need to develop a Situationist style revolution in our personal lives,<sup>20</sup> seeing possibilities for play and change in older age rather than the fag end of a life and a period conceived of as a burdensome inconvenience by popular culture and the state. There is no reason why we shouldn't have fun under these circumstances, wearing purple, shaking up the youthquake, tearing apart the boxes with our grandchildren and with older allies around the globe, rebranding older age as a fulfilling and productive time rather than as something to be feared.

We need to live our older ages in such a way as to be the changes that we want to see. In the end, we are all in this together.

Vera Bolter is the founder member for the Elders Council, an old age activist and an indomitable fighter for positive change. In a recent HAPPI report (Barac and Park, 2009) she said:

We need to encourage people to think ahead and work to raise expectations. Unless you have a vision about how things could be you will be confined by what is available now.  
(Vera Bolter MBE)

# Notes

## Themes, structure and background assumptions

1. This paper uses the phrase 'older people' as a term applying to people of 55 and up. Starting older age from the 55<sup>th</sup> birthday is increasingly a standard convention, perhaps because it is the age at which people can apply for sheltered housing in the UK. The phrase 'older people' itself is not popular. Many people (from 55 to 100) will have objections. 'I don't feel old', is a perfectly reasonable one, for a start. So the term feels like an insult to some – and lacks precision, since accepting oneself as old has much to do with self definition (or denial). For the purposes of this paper, however, people up to and beyond 65 will be regarded as the younger old, whereas older old applies from 75 but becomes more applicable at around 85, when dependency levels go up very steeply. Apologies to the numerous people this arbitrary definition will offend – and any suggestions for alternatives are very welcome.
2. With some reluctance it was decided not to discuss the white paper *Building the National Care Service* (HM Government, 2010) at length within the body of this paper as it remains a theoretical construct rather than an example of actual practice. However it is worth noting that the white paper contains some welcome ideas. These include agreed national standards for eligibility for care, an intention to provide more care at home, 'free' care and agreed funding for this, ruling out a simple increase in general taxation. However, as many commentators have pointed out it is difficult not to see the paper as at least in part the product of election pressures, with some awkward decisions deferred (e.g. delays on national standards/eligibility criteria, and yet another debate on funding) and some issues not apparently well thought through (e.g. potential perverse incentives effectively encouraging councils to place more people in residential care, little concrete consideration of how re-ablement and prevention might work). Nonetheless, the white paper remains a consistently interesting document, which one hopes will provide a basis for change in the future, whatever party is in power after May.
3. The debate on 'death tax' and the inability of politicians to engage with one another at a recent Age UK summit are depressing examples.
4. For a list of policies, including the widely misunderstood 'free personal care' issue, see [www.snp.org/search/node/older+people](http://www.snp.org/search/node/older+people).
5. The system of proportional representation in Israel has historically seen a number of candidates elected to power on the basis of the single issue of older age.
6. There is a clear sense in which discussion of innovation risks glossing over the need to actually deliver on promises that have already been made: an emphasis on change is often used to smuggle out broken pledges or to divert attention from services that would have functioned perfectly well if enough money and/or energy had been dedicated to them.

7. The Alzheimer's Society report *Counting the Cost* pointed out that many people living with dementia are in hospital unnecessarily, which is inappropriate and frequently actively harmful. It estimates potential savings of £80 million per year to the NHS for people with dementia alone.  
See <http://www.alzheimers.org.uk/countingthecost>
8. For work on the Department of Health/NHS End of Life Care Strategy, see <http://www.endoflifecare.nhs.uk/eolc/>.
9. Recent UK collaborations have included organising a visit to the UK by the Canadian Institute of Ageing.  
<http://www.cihr-irsc.gc.ca/e/8671.html>

### **Joy in the evening: Current good practice**

1. Communities and Local Government (CLG) is a well funded and organised quango dedicated to working for 'safe, prosperous and healthy communities'. See [www.communities.gov.uk](http://www.communities.gov.uk).
2. See [www.firststopcareadvice.org.uk](http://www.firststopcareadvice.org.uk).
3. Elderly Accommodation Counsel is a national charity set up to help older people make informed decisions about meeting their housing and care needs. See [www.housingcare.org](http://www.housingcare.org).
4. Counsel and Care gives advice to older people, their relatives and carers across the UK and is much involved in research and campaigning work. See [www.counselandcare.org.uk](http://www.counselandcare.org.uk).
5. Age Concern and Help the Aged are the two largest and best established charities working with and for older people in the UK, with complex, overlapping local/national structures, which cause some tensions. They have recently merged as Age UK.  
<http://www.ageuk.org.uk/>
6. See <http://www.nhfa.co.uk/index.html>.
7. The recent White Paper *Building a National Care Service* (HM Government, 2010) suggests a single website portal for information on the National Care Service. However, it is worth noting both that many older people are not currently on line (see Assistive Technology section of this paper) and that such a site would still add to the present bewildering proliferation of advice rather than simplifying it. There are some good ideas about utilising libraries, GPs and pharmacies, however.
8. See [www.eapa.org.uk](http://www.eapa.org.uk).
9. See [www.employeeassistanceprogramme.com/article1\\_print.htm](http://www.employeeassistanceprogramme.com/article1_print.htm).

10. See [www.bupa.co.uk/business/all-business/employee-assistance](http://www.bupa.co.uk/business/all-business/employee-assistance).
11. See [www.kent.gov.uk/adult\\_social\\_services/your\\_social\\_services/advice\\_and\\_guidance/assess\\_your\\_needs\\_online.aspx](http://www.kent.gov.uk/adult_social_services/your_social_services/advice_and_guidance/assess_your_needs_online.aspx).
12. See [www.liquidlogic.co.uk/adult-system](http://www.liquidlogic.co.uk/adult-system).
13. See [www.contact-the-elderly.org.uk](http://www.contact-the-elderly.org.uk).
14. See [www.sdwg.org.uk](http://www.sdwg.org.uk).
15. The Lewy Body Society helps spread awareness of this form of dementia, where accurate diagnosis means much more effective treatment: it is easy to mistake the illness for Alzheimer's disease or Parkinson's disease but in both instances some standardly used drugs can worsen dementia with Lewy bodies. See [www.lewybody.org](http://www.lewybody.org).
16. [Web.mac.com/danutalipinska/DL/Home.html](http://Web.mac.com/danutalipinska/DL/Home.html) is an interesting website and has some useful commentary on Danuta Lipinska's work.
17. For example, high incidence of diabetes in Indo-Asian communities and their diasporas and problems with anaemia in Afro Caribbean communities.
18. Age Concern Hackney and LinkAge work in Tower Hamlets are personal favourites but there are many groups across the UK in much the same case.
19. This can be appallingly difficult for people who have been bi or multi lingual and who find themselves living with dementia: there is a tendency to switch between fragments of languages that requires carers with equal language capacities and a cryptic crossword/Finnegans Wake knack for decoding. It is a real and increasing problem that needs investigation.
20. It is worth noting that though this blindness has negative consequences (sometimes meaning confining older people as a result of a familial sense of shame) it can also have positive aspects, with older people retaining high status as heads of families.
21. Tel. 020 8765 7718. It's a great pity Kent County Council haven't found space on their website for this unique and remarkable centre, run by Shaminder Singh Bedi OBE.
22. See <http://www.ageconcernleics.com/leicesterforum/>
23. The experiment has been tried in the UK more than once, collapsing through lack of demand: for most in the LGBT community there is a feeling that genuinely tolerant residential environments are sufficient and locatable. Exclusively gay options exist in the US, in the Netherlands, in Germany and elsewhere in Europe, however.

24. See [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?categoryID=200137&documentID=1099](http://www.alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200137&documentID=1099) for advice from the Alzheimer's Society.
25. Contact [lgbtsupport@alzheimers.org.uk](mailto:lgbtsupport@alzheimers.org.uk).
26. See <http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/older-lesbian-gay-and-bisexual/?paging=false>. Since Help the Aged can demonstrate goodwill but less active involvement it is to be hoped that this aspect of Age Concern's work survives the merger of the two organisations.
27. See [www.alzscot.org](http://www.alzscot.org).
28. See <http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm>
29. See [www.dementiauk.org](http://www.dementiauk.org).
30. See <http://news.bbc.co.uk/1/hi/health/7865494.stm>
31. See Richard Taylor's website at [www.richardtaylorphd.com](http://www.richardtaylorphd.com). Essentially the lecture is a moving evocation of the reality of living with dementia linked to a well-thought through examination of the morality of social attitudes to dementia. The lecture points out the extent to which we dehumanise the condition by reducing it to an illness to be treated rather than an existential dilemma that anyone could face at any time.
32. See <http://www.dwp.gov.uk/policy/ageing-society/resources-good-practice-reports/linkage-plus/>. This work was based on 'sure start in later life' principles.
33. Sharing some interesting similarities with the Government's *Total Place* initiative (HM Treasury, 2010). See [www.hm-treasury.gov.uk/d/total\\_place\\_report.pdf](http://www.hm-treasury.gov.uk/d/total_place_report.pdf).
34. See [www.housing21.co.uk](http://www.housing21.co.uk).
35. See [www.dementia-voice.org.uk](http://www.dementia-voice.org.uk).
36. See [www.mha.org.uk/Hs10.aspx](http://www.mha.org.uk/Hs10.aspx)
37. See [www.dhcarenetworks.org.uk/independentLivingChoices/Housing/HousingRegions/Eastern/?parent=10248&c](http://www.dhcarenetworks.org.uk/independentLivingChoices/Housing/HousingRegions/Eastern/?parent=10248&c).
38. See [www.idea.gov.uk/idk/aio/1108789](http://www.idea.gov.uk/idk/aio/1108789).
39. See [www.housingcorp.gov.uk/server/show/ConWebDoc.11005](http://www.housingcorp.gov.uk/server/show/ConWebDoc.11005).

40. See [www.belong.org.uk/macclesfield.php](http://www.belong.org.uk/macclesfield.php).
41. See [www.anchor.org.uk/PropertiesAndCareHomes/PropertiesForSale/DenhamGardenRetirementVillage/default](http://www.anchor.org.uk/PropertiesAndCareHomes/PropertiesForSale/DenhamGardenRetirementVillage/default).
42. See <http://www.sandford.stmonicastrust.org.uk/localinfo.asp>
43. See [www.isoomena.fi](http://www.isoomena.fi).
44. See the HAPPI report (Barac and Park, 2009) and also Daelhoven (the 'nursing home without walls') [www.designcouncil.info/mt/red/archives/2005/11/ageing\\_graceful.html](http://www.designcouncil.info/mt/red/archives/2005/11/ageing_graceful.html).
45. This suggestion was made by Domini Gunn, Lead Housing Inspector for the North West for the Audit Commission in discussion with Imogen Parry of EROSH and the author.
46. Or should this be under 'floating support'? [http://www.pbs.org/nbr/site/research/educators/060106\\_04d/](http://www.pbs.org/nbr/site/research/educators/060106_04d/).
47. See [www.myhomelife.org.uk](http://www.myhomelife.org.uk).
48. For example, Sue Benson, Hawker Publications and Sherin Hart, Methodist Housing Association.
49. Note that involvement in the community is stressed by the *My Home Life* programme, by the National Care Forum's new quality management systems and by the International Association of Homes and Services for the Ageing (IAHSA) on an international level.
50. For example, The Russets, St Monica's Trust, David's House, Methodist Housing Association and Threshfield, Barchester Healthcare to name three homes that the author knows, admires and has written about elsewhere.
51. For example, Barchester Healthcare (on a very localised basis, effectively involving flats, bungalows and houses under their own ownership) or Community Integrated Care (CiC) on a much less localised basis. Both companies have deservedly good reputations.
52. See <http://www.agedcare.org.au/PUBLICATIONS-&-RESOURCES/General-pdfs-images/Delphi%20technique%20Summary%20Q%201%20&%202.pdf>. Look for 'Homeshare'.
53. This excellent report by King and colleagues (2009), which deals with the broad issue of floating support and the very poor record of consultation on its introduction by Councils, much resented by many sheltered housing residents, is admirably fair minded. See

[http://policy.helptheaged.org.uk/NR/rdonlyres/652BC405-AA9E-49CB-B7FE-E16A7B0D3A99/0/nobodys\\_listening.pdf](http://policy.helptheaged.org.uk/NR/rdonlyres/652BC405-AA9E-49CB-B7FE-E16A7B0D3A99/0/nobodys_listening.pdf).

54. Pilot projects look promising. Evaluation is still to be completed, however.
55. The definitive books on the subject are 'Cohousing' by Kathryn McCamant and Charles Durrett and 'Senior Cohousing Handbook: A Community Approach to Independent Living', by Charles Durrett. See reference list.
56. For example the Older Women's Cohousing Group and other participants at the 'Affordable Cohousing' conference, 26<sup>th</sup> April 2010.
57. Supporting the conference cited in note 56, for example
58. See [www.nnrha.ie](http://www.nnrha.ie).
59. See [www.designandhealth.com/uploaded/documents/International-Symposium/Elderly-Care-by-Design/Mikael-Paatela-180210.pdf](http://www.designandhealth.com/uploaded/documents/International-Symposium/Elderly-Care-by-Design/Mikael-Paatela-180210.pdf).
60. See [www.homesandcommunities.co.uk/housing-Ageing-Population-Panel-Innovation](http://www.homesandcommunities.co.uk/housing-Ageing-Population-Panel-Innovation).
61. See Argyle and Bute Case Study  
[www.tunstall.co.uk/assets/literature/ADLife%20-%20Argyll%20and%20Bute.pdf](http://www.tunstall.co.uk/assets/literature/ADLife%20-%20Argyll%20and%20Bute.pdf).
62. See [www.external.stir.ac.uk](http://www.external.stir.ac.uk).
63. See [www.newdynamics.group.shef.ac.uk](http://www.newdynamics.group.shef.ac.uk).
64. See [http://www.sparc.ac.uk/about\\_kt\\_equal.asp](http://www.sparc.ac.uk/about_kt_equal.asp)
65. See [www.devicesfordignity.org.uk](http://www.devicesfordignity.org.uk).
66. Together with the Economic and Social Research Council and the New Dynamics of Ageing project.
67. The author's favourite (if only for the name, which sounds like a Marvel superhero). Professor Fernie is also responsible for a wheelchair that will move sideways, a boon in confined spaces. See <http://www.torontorehab.com/Research/Researchers/Research-Profiles/Geoff-Fernie.aspx>
68. See [www.hertsdirect.org](http://www.hertsdirect.org).
69. Email [vop@manchester.gov.uk](mailto:vop@manchester.gov.uk).
70. A particular favourite of the author's is Hackney Age Concern, a multi ethnic, politically diverse but never less than radical grouping.

71. There is a strong case for pooling knowledge and strengths here. Older people with high support needs and people with disabilities are overlapping sets; when older age communities need to consider how they link with younger people to avoid aridity they need to think about younger people with disabilities, too.
72. There is a danger that a general politicisation of older age, particularly younger old age, may marginalise people with high support needs. On the whole, however, groups like the Greater London Pensioners Forum have a good record in this regard.
73. See <http://www.elderscouncil.org.uk>. Look for the Older Person Friendly City Group.
74. David's House, a Methodist Housing Association home in Harrow has pioneered a low tech version of this mapping exercise, under the direction of manager Sherin Hart.
75. See [www.aunt-sue.info](http://www.aunt-sue.info).
76. See [www.pbs.org/nbr/site/research/educators/060106\\_04d/](http://www.pbs.org/nbr/site/research/educators/060106_04d/). The fee is about 40 dollars per month and the concept is being explored by a number of council equivalents. Whilst some aspects of this service would clearly fall foul of cultural and legal differences it is possible to imagine some interesting variants.
77. See [www.endoflifecare.nhs.uk/eolc/](http://www.endoflifecare.nhs.uk/eolc/) for work on the Department of Health/NHS End of Life Care Strategy.
78. For a tough minded and well informed introduction to the subject, see Ken Worpole's excellent *Modern Hospice Design* (2009).
79. See <http://liv.ac.uk/mcpcil/liverpool-care-pathway>.

## **Building on current innovation: Conclusions and thoughts**

1. Guardian Conference, Older People and Ageing Britain, December 2009.
2. Older people report feeling that they are asked the same questions again and again – and that services do not really change as a result.
3. This point has been forcefully made by Tom Noon (Cordis Bright) in a number of recent presentations. Certainly careful examination of the pilot studies carried out indicates they did not yield the expected savings (estimated at as high as one third by some very optimistic councils) for services offered to older people. In fact these services seem to have been at least as expensive as those more traditionally commissioned.
4. The cross party consensus on the introduction of Individual Budgets is an example of the rhetoric of choice, through which the word runs like a mantra. Whilst few genuinely believe that greater choice is anything less than a Good

Thing there are issues that a concentration on increased choice smuggles out of consideration. It means discussion of ageing and resources focuses on the slicing of the cake not its size. Is the ability to make a choice between adequate nutrition and keeping warm if I am an older person with high support needs a Good Thing? Does presentation of choice as the highest good eliminate from political discussion a debate about what constitutes basic rights? Does a relentless praise of choice effectively distract attention from the question of whether these choices are being made on a level playing field? These are complex ethical and political questions. From a pragmatic perspective and in the historical context of this paper, the author believes they can be finessed. As the increasing numbers of older people with high support needs take more political power (and as politicians become more conscious of it) the balance of resources and the language of rights will shift in our favour... for better or worse. Finessing the issues does not mean they disappear.

5. This is to neglect, sadly, the very real need for globalisation of this discussion: numbers of older people in the developing world are increasing significantly faster than those in the developed, for example, and there are far fewer resources to deploy.
6. Interestingly, Japan has begun work on a programme with this intention, increasing home care input. See [www.mhlw.go.jp/english/topics/elderly/care/6.html](http://www.mhlw.go.jp/english/topics/elderly/care/6.html) and [www.wao.or.jp/yamanoi/report/lunds/1&2.htm](http://www.wao.or.jp/yamanoi/report/lunds/1&2.htm).
7. Also see pilot work on joint commissioning between health and social care in Torbay and Hammersmith and Fulham. See <http://www.torbaycaretrust.nhs.uk> and <http://www.hf.nhs.uk/JSNA>.
8. See Tribe *et al.* (2009) for an example of services already being delivered by older Chinese people to older Chinese people.
9. Suggestion from Clive Bowman, BUPA, who also offers the thought that older people's actual spending/purchasing should be more closely monitored across the board, with an eye to facilitation of helpful change.
10. Japan is going through a similar process but is at an earlier stage: a brief summary of differences in perspectives from generations can be found in Schröder-Butterfill (2005) and followed up from there. See [http://www.iias.nl/nl/39/IIAS\\_NL39\\_23.pdf](http://www.iias.nl/nl/39/IIAS_NL39_23.pdf).
11. One million older people in the UK feel socially isolated. See Cattan (2001). <http://celebrate.mtcserver4.com/images/cmsimages/media/publications/healthsoc ialcare/isolation.pdf>
12. Everything from shared sexuality to a passion for golf.
13. The 'key community' phrase literally suggests the helpful (and relatively common) practice of mutually keeping copies of front door keys from selected neighbours

but can extend much further – see Stephen Burke’s sister paper for the Better Life programme, or *Key Communities, Key Resources* (Communities and Local Government, 2008) for an example of thought about faith communities, surely still the most natural ‘artificial families’ in the UK. See [www.communities.gov.uk/documents/communities/pdf/846112.pdf](http://www.communities.gov.uk/documents/communities/pdf/846112.pdf).

14. There is surely a case for a UK/European equivalent to the US ‘Gray Panther’ movement, a forum for debate, a focus for lobbying and a source of strength. See [www.graypanthers.org](http://www.graypanthers.org).
15. The estimable Sheena McDonald is looking at possibilities for a channel.
16. Paradoxically picking retro examples, re-running Coronation Street; making a conscious decision to avoid violent TV or TV in aggressively bad taste; re-setting parameters defined by a conception of selling to youth supposedly in thrall to the continuously shocking. Many people of all ages find the relentless boundary pushing for its own sake of current programming irritating and offensive.
17. A fellow member of the Better Life board suggested an advertising campaign on billboards, with positive images of older people captioned; ‘Relax: You’re Ageing!’ Make your own fun: further suggestions are welcome.
18. The church and faith communities must surely take a more active role in breaking these prejudices down, too.
19. Thanks to Deborah Sturdy for the suggestion, in which the author is trying to interest the great and the good (or at least the great).
20. Where are the Sex Pistols when their generation needs them once more? Busy being a nostalgia act, unfortunately, fit only for Butlins punk revival nights or entertaining the wealthy on ocean liners. Time to call on extant punks still in pursuit of the ineffable: The Slits, or Alternative TV: ‘Vibing Up The Senile Man’, indeed.

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## Quotations from survey responses

### What do you most want for yourself when you are older?

'Real options and opportunities, not one size fits all'

'Sharing experiences so that others can benefit'

'Company of others'

'To retain my *joie de vivre*'

'Policy input'

'Simplicity'

'I would hope that my family and friends would provide time for my social wellbeing – but I would not wish my care to be a burden on them'

'Though ... I would prefer to remain in my personal castle I acknowledge my care needs may be better served in a care facility'

'I want people to have time for me'

'As a Bangladeshi I would say normally people have good links with their family...full support from\their family members'

'A range of interests'

'Good health'

'Loneliness is the great fear for me, so my greatest desire is still to have strong social connections'

'I'd like to live in the UK half the year and Italy the other half!'

'Companionship and affection – they're as vital as food and drink'

'I don't want to live beyond the point where I am at the mercy of others'

'My own garden. Pets. A shooting range!'

'My records to be kept accurately and not to be shared with anyone'

'Protection of my dignity'

'To have someone to keep a daily eye on me, to see fairly quickly whether I have had

a fall, a stroke, a chest infection, etc.'

'Supportive kids'

'My relationship with God respected'

'One-stop-shop where I could refer my problems with relative ease'

'Help in my own home with cleaning, odd jobs, gardening, hairdressing, chiropody, dressing, meals, shopping, personal hygiene etc., as and when these become necessary. I could pay for all these, but if I couldn't – I'd like them free, or subsidised'

'Political engagement'

I live with the symptoms of dementia, which together with ageism in society double damns me to be treated as someone who is fading away'

'To still be making a difference – and to be respected for making a difference'

'A right to debauchery'

'To be able to tell people when they are not doing the things I would like without fear of withdrawal of services'

'Given that public sector pensions probably won't deliver I want public services as strong as private'

'I do not want to be discriminated against because of my age... or piercings, hair colour, the clothes I'm wearing. I started my life as a radical and I may end in the same manner'

## **If you had high support needs what could be done to help you achieve you goals?**

'Someone who will act as a 'trouble shooter' on my behalf'

'Finding someone who is honest, reliable, knowledgeable, who would be able to signpost me in the right direction'

'Independent living at affordable prices'

'This is about mobility and technology, I think'

'Input from family and friends'

'A facility that is purely for Bangladeshi elders'

'A clear description of what can be provided... confidence that I was getting a fair deal'

'Living in a complex with other people where we helped each other out'

'A clear description on what can be provided on my behalf'

'Staff chosen by me'

'Not having to sell my own house and lose all my savings'

'... professional assessment and prognosis. No castles in the sky, thank you!'

'Someone with personal skills and wide ranging knowledge of entitlements'

'Effective pain relief – street drugs and a stiff drink if necessary!'

'Someone to help me organise plans for the day – and for the year'

'If all else fails an opportunity to leave this world at a time of my own choosing'

'I need people who love me and appreciate me for my wholeness'

**What strikes you as the best help towards better lives for older people in the community with high support needs available currently, here or abroad?**

'Retirement villages where full time carers are on hand but people live independently'

'The Housing 21 end-of-life dementia nurse project'

'Assistive technology ... with ethical protocols.. and proper human back-up'

'...clear entitlement and understanding of the limits of that entitlement'

'People need to be meaningfully engaged with the wider community'

'In France...risks and outcomes are shared in a partnership between the state and family, with local government being responsible for funding'

'Human face to face contact is a need for older people. Spain finances work done by family carers'

'From my experience across health and social care the best help is provided by high quality, tailored support by people who are skilled, knowledgeable and can offer flexible support'

**Any thoughts you would particularly like to add?**

'For someone to take the lead ... so that others can follow'

'I would suggest a case for the equality rights commission'

'Blind adherence to keeping people in their own homes is as bad as any other blind adherence'

'Basic health and safety and risk management should be part of a national operating system'

'During my husband's illness we were "assessed" at least six times by various organisations, a lengthy and time-consuming process which could have been done once, and the information made available to each agency'

'I imagine days of desolation and other days of anger'

'We need genuine collaboration across sectors'

'Older people need to be re-branded as cool'

'As has been exposed by Panorama...the quality of life for some people living in their own homes...is an impoverished imprisonment'

'Time out to reflect on personal aspirations in old age helps to focus attention on changes needed'

'If we can achieve high quality care and support in areas like cancer and children's care why can't we do it for older people, who are often vulnerable and deserve specialist services?'

'There are NHS workshops planned that describe the role of a care home in terms of productivity in admission avoidance rather than quality and dignity for the older person – this is an awful way to look at the service'

'What can we do for people with high support needs that enables them to contribute and feel needed?'

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