C|P|A *briefings*

OLDER PEOPLE'S VISION FOR LONG TERM CARE

THE CENTRE FOR POLICY ON AGEING (CPA) worked in partnership with The Older People's Programme (OPP) to explore older people's experiences of living with high support needs focusing on those moving to and living in care homes now, and using other kinds of supported accommodation or living arrangements (e.g. extra care and adult placement schemes) – a project commissioned by the Independent Living Committee of the Joseph Rowntree Foundation. The aim is to identify the critical elements of independent living for older people with high support needs.

Older people with significant support needs constitute a large and growing sector of the population; yet they have often been left out of innovative service and practice developments. Recent initiatives around independent living support that enables individuals to have choice and control in their lives have been slow to engage with and respond to the varied needs of older people. For example residential care is too often still the norm or regarded as the only feasible option for older people, especially those aged over 85 years and/or those with high support needs. Person centred planning has been shown to be an effective approach with older people but is happening only for small numbers of individuals in a few forward thinking localities.

The key challenge is to distil the essential features of independent living for older people – both for those who are at the threshold of needing some kind of continuous and intensive support and for those living in supported accommodation including residential and nursing homes. This encompasses the following issues for older people:

- Exercising choice and control
- Options and opportunities about where you live and who you live with
- Person centeredness and what this means in practice
- Independence, independent living, prevention - and what these mean for older people with high support needs and/or degenerative conditions
- Providing and commissioning different kinds of support – service and 'non-service' based solutions/support

The project comprised a scoping study to gather information about the current range of approaches, options and opportunities; in-depth fieldwork in four localities to explore innovative practice with a range of stakeholders; a sounding board event; and a report bringing together key messages and action for change.

Key messages

The project identified the following key messages which have emerged across all phases and elements of the work:

- The lack of a voice for older people with high support needs.
- The need to learn from the reasons why older people move 'into care'.
- That the current situation is unacceptable, and there is a need for fundamental change.
- The dominance of money and the market in long term care.
- The need for a strong vision, based on older people's vision for a good life.
- The recognition that huge cultural change, as well as structural changes to what's available, is required; as well as how it is funded, commissioned and delivered.

The central message is that the voices of older people who need a lot of support in their lives are so quiet as to be practically absent, or indistinguishable from the range of other people who speak on their behalf (professionals, relatives, commissioners, policy makers and politicians). If you have no voice, you cannot exercise choice and control over your support, or indeed any aspect of your life.

The need for a strong Vision, based on older people's vision for a good life

An understanding of and focus on voice, choice and control – on self determination and personhood – is missing for older people with high support needs.

This gap is evidenced at all levels:

- in individual experiences of the support people receive and the options open to them;
- in terms of wider support and commissioning decisions that affect local communities;
- in the research, and policy frameworks that influence and guide practice.

Whilst recent strategies and policies seek to address this, much needs to be done to increase the strength and influence of older people's voices when they need a lot of support; and to increase their choice and control over that support.

Cultural and structural change

One of the first messages to get across is that this is not just about 'dignity and respect' – current cornerstones of government policy and best practice guidance on long term care. This is about a completely different approach based on citizenship and a focus on personal identity, self expression, individual aspirations and fundamental human rights. This requires a much deeper understanding of what needs to be changed from older people's perspectives to have a good life, rather than professionals' views about quality services alone.

In the phases of the project that tested and explored the emerging Vision of a good life it was clear the majority of 'project stakeholders' believe that ageism and stigma (of extreme old age, frailty and intensive support) is rife – in services, in communities and in family life. A conclusion is that older people with high support needs are not consistently well served by public services and existing statute and local authorities' duty of care.

At the same time, individuals, families, friends, neighbours and professionals report they often battle to achieve a good life for an older person close to them – and find themselves defeated by structural and attitudinal barriers (eligibility criteria, lack of information and

advice, lack of interest) and staying power to see things through and implement local actions (booking housing repairs, ordering equipment, checking on progress).

Evidently there are huge cultural as well structural shifts that need to take place for a Vision to be achieved. As a first step, the report, drawing together all strands of the project, presents the elements of – or Keys - to a 'Good Life' and considers: what makes this good life possible for older people with high support needs? This is the emerging Older People's Vision.

Older People's Vision: Keys to a Good Life (for older people with high support needs)

During the fieldwork a great deal of feedback was received from older people with high support needs and representatives of organisations and groups who support older people, about what contributes to 'a good life' when you need a lot of support in your life. The outcome was a framework picture that represents the 'Keys to a Good Life'.
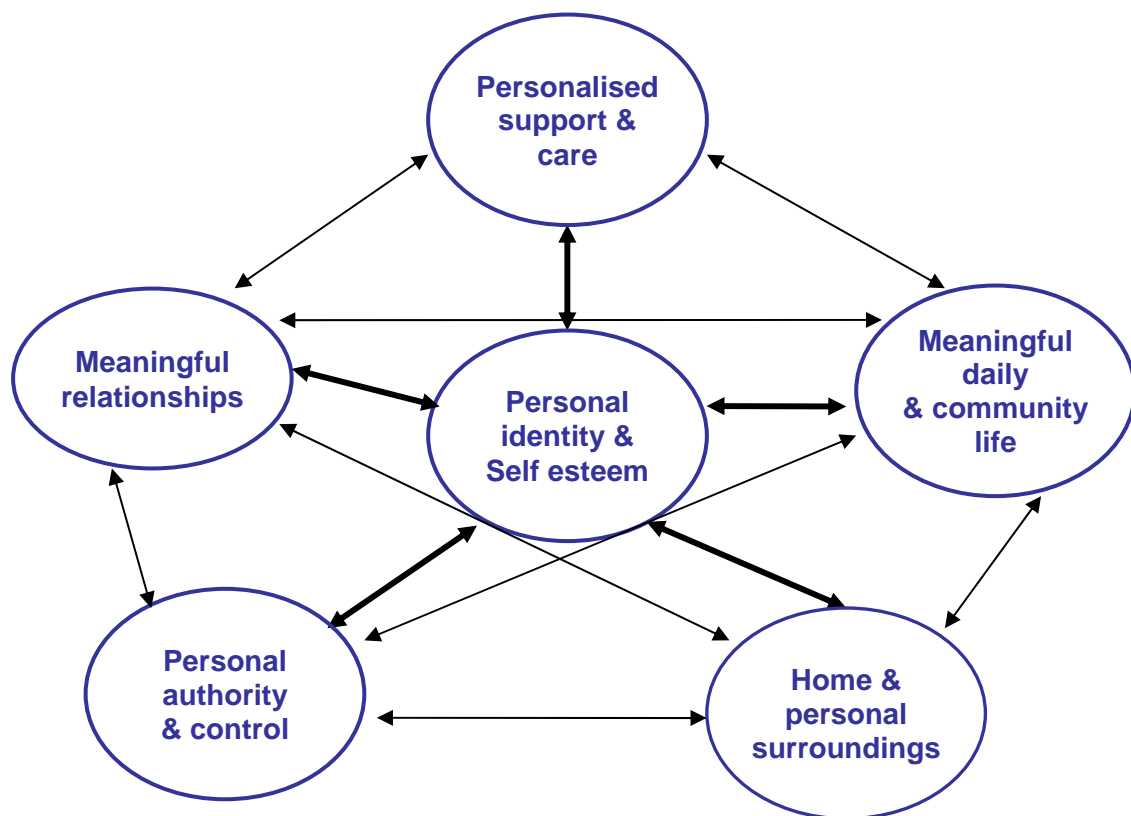
While these elements are not unique to older people with high support needs, meeting older people's own aspirations for these different elements is often extremely difficult if you need a lot of support and especially if living in residential care. The central element – personal identity and self esteem – is often underplayed or not recognised in services and support arrangements.

Developing an agenda for change

The full report sets out an outline agenda for change in order to take this work forward. There are three components to this agenda, each of which needs to be addressed at three levels.

<table>
<tr><td>

3 Components of Change

1. A clear steer towards and action to deliver independent living and equal access to self directed support for older people with high support needs.
2. A completely different approach towards, attitudes about and relationships with older people who need a lot of support in their lives.
3. A focus on choice and control and access to high quality support for older people who need intensive and end of life treatment/care.

</td><td>

3 Levels Where Change Required

a) For and with individuals who need support and their families.

b) Locally for organisations and staff providing and commissioning that support.

c) Nationally for public policies and public services, as well as social care systems and the care market.

</td></tr>
</table>

By taking forward this work the aim is to bring about radical change that fundamentally shifts the way we all think about, talk about and respond to the needs and aspirations of older people with high support needs. It is all too easy to revert to structural solutions to complex problems, meaning that existing attitudes, perceptions and negative stereotypes prevail. Interventions are needed that promote a much deeper understanding of the issues in this study, in order to encourage and influence positive attitudes, beliefs, behaviours and actions.

Close attention also needs to be given to the concurrent debates taking place around 'long term care', not least the funding debates surrounding the Department of Health's green paper on the future of social care. There are four key interest groups that need to be engaged in future work to progress older people's vision for long term care:

1. Policy development and implementation, including the cross government Independent Living Strategy; *Putting People First,* the DH's concordat for personalised support; the Green Paper discussions on funding for social care; and the housing strategy for an ageing population, *Lifetime Homes, Lifetime Neighbourhoods*.
2. Changes to inspection and regulation arrangements through the development of the Care Commission
3. Wider developments taking forward opportunities for self directed support, such as in Control
4. Programmes designed to increase options and improve quality of life for older people who currently live in residential and nursing homes and extra care housing (e.g. My Home Life, Dignity in Care initiative and the implementation of the Housing Strategy for an ageing population).

The final report published November 2009 is available to download from the JRF website
http://www.jrf.org.uk/publications/older-people-vision-long-term-care

For further details of the CPA's work on long term care, and other areas, contact the Centre's Director, Gillian Crosby, email gcrosby@cpa.org.uk   Access government policy documents via CPA's website www.cpa.org.uk/cpa/policies_on_ageing.html   and selected reading lists at www.cpa.org.uk/information/readings/readings.html

February 2010