

Response to the Dilnot Commission on the Funding of Care and Support

Submission by the Joseph Rowntree Foundation

January 2011

The Joseph Rowntree Foundation (JRF) is one of the largest social policy research and development charities in the UK. For over a century we have been engaged with searching out the causes of social problems, investigating solutions and seeking to influence those who can make changes. JRF's purpose is to understand the root causes of social problems, to identify ways of overcoming them, and to show how social needs can be met in practice. The Joseph Rowntree Housing Trust (JRHT) shares the aims of the Foundation and engages in practical housing and care work.

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Executive summary

The Joseph Rowntree Foundation (JRF) and Joseph Rowntree Housing Trust (JRHT) welcome this opportunity to respond to the Dilnot Commission's Call for Evidence. For over 15 years, JRF has been calling for reform to the current funding system. JRF recognises fully the scale of the task ahead of the Commissioners.

Key points

JRF evidence supports the Commission's analysis of the challenges and opportunities, strengths and weaknesses. In addition, our evidence highlights:

- The necessity of recognising the potential impact of the current reduction in local budgets and care spending. Inadequate investment (e.g. in low-level support or prevention) over the next few years could impede the successful implementation of reforms in the future.
- The value of prevention or 'that bit of help' (low-level support) to people and to the public purse (Centre for Policy on Ageing 2011).
- The critical importance of judging any proposed reforms against their capacity to do the following:
 - support and facilitate achievement of the outcomes that people themselves want, value and need for a good life;
 - incentivise investment in low-level support or prevention;
 - stimulate the development of responsive and alternative approaches (in the private sector as well in communities, families and services);
 - challenge negative images of ageing, disability and long-term illness at the same time as requiring or encouraging people to increase their contribution to the costs of care (irrespective of the proposed model).

Our response draws attention to JRF evidence in relation to:

- the outcomes that people themselves want and value for a good life – outcomes which are often unmet and unrecognised by the current system;
- the growing diversity of people who require care and support;
- the importance of supporting informal carers;
- considerations relating to housing, care and support.

Conclusion

JRF does not advocate for any one funding model over another but we do urge the Commission to propose reforms which support the achievement of user-defined outcomes as such a system should also be better equipped to flex and adapt to future changes. Above all, JRF urges the commission to be radical and forward-thinking in its deliberations, as well as evidence-based.

Introduction

Joseph Rowntree Foundation (JRF) and Joseph Rowntree Housing Trust (JRHT) welcome this opportunity to respond to the Dilnot Commission's Call for Evidence.

JRF has long called for reform on the basis of evidence from research (JRF) and our experience as a provider of housing and care services for older people and younger disabled adults in Yorkshire and North East England (JRHT). We recognise fully the scale of the task faced by the Commissioners. We urge the Commissioners to be radical and far-thinking, as well as evidence-based, in their search for solutions.

Our response addresses the three questions and provides full links (in the References) to additional evidence on our website (www.jrf.org.uk). In two cases, we refer to forthcoming evidence due to report later this year.

Question 1: Do you agree with the Commission's description of the main opportunities and challenges facing the future funding of care and support?

The Commission describes four areas in which change brings challenges and opportunities. It is, inevitably, the complex interactions across these (demographics, care needs, wealth and assets, and social or technological trends) that presents the biggest challenge in designing a future-proofed funding system. Below, we point to JRF evidence that the Commission may want to explore in more detail.

Different populations and groups, including differentials in wealth and assets

Improvements in technologies, medicines and treatments for ongoing conditions and impairments are significant. Although future morbidity is hard to predict, there is already evidence regarding the increasing diversity of the new generation of older people which present wholly new challenges for the delivery and finding of care. A recent review of the demographic profile and trends among older people with high support needs (Falkingham, *et al*, 2010) and of equalities and diversity issues among this group (Blood and Bamford, 2010) illustrates that population groups that may have been small or relatively 'invisible' are expanding or becoming more visible (e.g. BME older people, older Gypsies and Travellers, LGB and transgender older people). Some 'new' groups are also emerging, such as people with learning difficulties who are living longer – a significant proportion are developing dementia (Watchman, *et al.*, 2010; Kerr, *et al.*, 2006).

A JRF study (Salway, *et al.*, 2007) on long-term ill-health, poverty and ethnicity which looked at Pakistani, Bangladeshi, Ghanaian and white English working-age people living with long-term ill-health, found that many respondents lacked coping skills and felt little control over their situation. People in all four ethnic groups concealed their ill-health. Minority ethnic respondents were particularly disadvantaged.

A recent JRF study of older people living with HIV (Power, 2010) showed that they face a series of complex challenges, which often differed from other populations. In particular they reported difficulties in accessing healthcare and need to know their rights. In terms of poverty, people with HIV aged 50 and over were generally, in comparison with their peers, less likely to be economically active and far less likely to have a financial cushion for their old age. Black African women were financially the worst off within this group and indeed had by far the hardest time overall, coping with poverty, poor housing, treatment access and migration issues as well as major HIV stigma within their cultures. Employment was a notably higher concern for black African women than the other subgroups in the study.

Technological and medical progress also mean that disabled children will increasingly experience transition to adult care services *and* transition to long-term care (65+) services. This means spanning across three different funding systems with varying eligibility criteria. Many groups – including people with both physical *and* mental health support needs (Morris, 2004), disabled parents (Olsen and Tyers, 2004), and disabled children transitioning to adulthood (Morris, 2002) already fall between the gaps of the current funding and delivery of care and experience negative outcomes.

Finally, and in relation to wealth and assets, a study based on 30 years of census data (Young, *et al.*, 2007) found that some 9 per cent of women and 4 per cent of men aged 65 and over and living in the community in 1991 were in institutional care by 2001. These proportions were slightly lower than the equivalent between 1981 and 1991. Characteristics associated with increased chances of moving into institutional care included older age, being unmarried, poorer health, being a tenant rather than an owner-occupier and, among women, having no children.

Changing expectations

This issue is highlighted by the Commission as an area where evidence is limited.

JRF has a growing body of research which has engaged different user groups on a range of issues, including their experiences of care and support and how far this meets their aspirations. This has provided insight into how expectations are changing across all care user groups (see Beresford, *et al.*, forthcoming; Mauger, *et al.*, 2010; Bowers, *et al.*, 2009; Glynn, *et al.*, 2008; Hart, *et al.*, 2007; Branfield and Beresford, 2006 and 2010; Innes, *et al.*, 2006; Godfrey. 2004). These include increasing expectations:

- of person-centred support, where users participate and engage in planning and managing their own care rather than receiving support in a passive way);
- that care and support will facilitate greater independence, independent living and social engagement, including in residential settings and among both working-age and older care users;
- that care and support will actually deliver a far wider range of outcomes than those narrowly falling within either health or social care – including supporting housing, leisure, social and family outcomes within local communities, and being able to achieve a ‘normal life’ or live on as equal terms as possible to non-disabled peers;
- that there will be possibilities for people who use care and support to be more involved in the wider design, commissioning, delivery, monitoring and evaluation of support and services generally.

Last year, JRF commissioned three think-pieces to challenge assumptions about care and support for older people with high support needs. The papers (Branfield and Beresford ,2010; Burke, 2010; Manthorp, 2010) draw together views from service users and family carers, along with examples of innovation or promising practice. We have since commissioned new research to explore *alternative approaches* based on *reciprocity and mutuality* involving older and younger people with high support needs. While this will not complete in time to inform the Commission, it highlights the appetite for different ways of living together and supporting each other (such as co-housing, or home-share schemes, or care co-operatives) and evolving expectations.

Developing the market

The challenges – and opportunities – of developing the market for care and support warrant greater recognition in the Commission’s analysis.

This is an area where JRF has little evidence, but we would urge the Commission to ask the questions:

- What has been the role of the current funding system (if any) in stifling innovation or market development?
- How might a funding system stimulate and incentivise a vibrant market that responds to what people want and value, and offers value for money?

Informal care

The Commission recognises the role of friends and relatives in delivering care informally as a means of significantly reducing the costs of formal care for individuals and the state. It warrants greater emphasis. The demands on informal carers are increasing as fewer people are deemed eligible for state funding, yet demographic, social and labour market trends suggest that high reliance on informal care may be unsustainable in the longer term.

In 2007, JRF published a report analysing the characteristics of people who provide unpaid care to family and friends, and characteristics associated with becoming a caregiver. Based on Census data over a 30-year period, the report also mapped poor health and deprivation among carers (Young, *et al.*, 2007). The report confirmed:

- geographic variations in England and Wales (giving unpaid care for 20 hours or more per week was highest in the North of England and lowest in the South East of England);
- informal caring was associated with disadvantage: higher in deprived areas and areas with higher level of poor health. Informal carers were relatively disadvantaged, more likely than their peers to be in poor health themselves, and less likely than their peers to be employed.

A funding system which is sustainable over the longer term must take into account that there will be fewer informal carers overall, more informal carers who must also work, and the knock-on and gender impacts of caring: unpaid carers are at a significant economic and social disadvantage, and this disadvantage falls disproportionately on women (Himmelweit and Land, 2008). Carers tend to be in poorer health themselves, but are often unwilling to ask for help (Walker and Walker, 1998) and feel the need to seem to be coping (Philips, Bernard and

Chittenden, 2002). Many people are mutually dependent (and therefore distinctions between 'carer' and 'cared-for' can be unclear).

As carers become older themselves, they will not have accumulated the assets they may need to pay for their own care, and may well need higher levels of care due to poorer health. A lack of support for informal carers will increase future care costs. Flexible working hours, the opportunity to reduce hours or take a career break without financial penalties, and good-quality, affordable support for carers and care recipients would help employees to combine care and work (Mooney, *et al.*, 2002).

Impact of budgetary spending cuts over the next parliament

The primary challenge in the short and medium term is the significant reduction in care and related funding over the course of the next parliament. While the Commission has a long-term remit, it must nonetheless recognise and bring to the government's attention the potential impact of spending cuts in the short and medium term which may see eligibility criteria rise even higher, and reduced investment in low-level or preventative services, as well as the provision of information and advice as funding is reserved for those in the most critical needs (Smith and Cavill, 2010).

The effects of inadequate funding and investment over the next four years could have serious negative implications for the successful implementation of a new funding system in succeeding years. As the Commission's stated objective is to consider social care in the round alongside welfare benefits, it is also important to recognise the potential impact on health and well-being that cuts to disability and pension benefits may bring, and the subsequent impact this may have on demand for NHS, public health and social care services.

Question 2: Do you agree with the Commission's description of the strengths of the current funding system, and its potential shortcomings? Do you think there are any gaps?

JRF supports the Commission's recognition of the following areas, and the Commission's commitment to create a funding system which:

- continues to provide a 'safety net' for *people in poverty*;
- supports personalisation – *supporting people to achieve the outcomes they themselves want and value*;

- maintains the policy focus on prevention – *stimulating and incentivising investment in prevention on the ground* ;
- balances locally responsive support with national access – *and clarity about national entitlements: what people can expect in return for contributing, both as individuals and as informal carers.*

Our evidence also supports the Commission’s analysis of the shortcomings: some people who face very high care costs can lose most of their income and assets; a complex system, difficult to navigate, and with low levels of public awareness; significant levels of unmet need; and a system that is widely felt to be unfair.

However, while recognising the Commission’s task is to propose reforms for the funding system (and not the delivery system), JRF strongly urges the Commission to consider carefully the inextricable links between *funding and delivery*. The Commission will have to assess the impact that any proposed reforms to the funding system will have on delivery, particularly those areas cited by the Commission as strengths, namely *prevention and personalisation*.

Prevention

In response to the Commission’s question, JRF believes that the current system does **not** put sufficient emphasis on prevention and supporting those with lower level needs. This is not only, however, a question related to ‘value for money’. Our evidence suggests the policy focus on prevention has been unable to deliver the level of investment or real change needed to meet the demand for low-level and preventative services. Significant unmet demand persists in this area (Raynes, *et al.*, 2006). It is in part because of the safety net approach that preventative care strategies are being overlooked, as the existing safety net strategy has targeted resources on the most acute needs and – particularly in a time of reduced budgets – counteracts any preventative policy focus through stringent financial disincentives (Smith and Cavill, 2010). This relationship is not mentioned in the weaknesses of the current system’s safety net approach and is a significant omission.

JRF agrees that a safety net, and a minimum entitlement for the most vulnerable, is a hallmark of a fair and progressive funding system (Stone and Wood, 2010; Keen and Bell, 2009), but there is also a risk that an exclusive focus on this will undermine the wider remit of a care funding model – which should be to facilitate and incentivise healthy ageing, early intervention and prevention in order to achieve a more socially and financially sustainable care system that is cost-efficient. We therefore

suggest that the disincentives to investing in preventative and low-level support which seem inherent in the current funding system are identified as a shortcoming of the system.

The evidence regarding the effectiveness of preventative interventions is less limited than widely dispersed. There is a good body of evaluative data and good practice available, alongside local evaluations relating to many different types of intervention. JRF's Older People's Inquiry identified dozens of preventative schemes of this type, and, while not all had rigorous evaluative data, several showed positive and measurable outcomes both to older people's health and well-being as well as their own sense of well-being and safety (Raynes, *et al.*, 2006). Other examples from JRF evidence include a JRF-funded evaluation of three pilots which increased physiotherapy and nursing in older people's care homes (through making more use of a community nurse or through providing health education and basic clinical and nursing skills training to care workers). This generated evidence of benefits and cost savings in terms of preventing hospital admissions and moves to nursing care, and facilitating early hospital discharges (Wild, *et al.*, 2010; Wild, *et al.*, 2008).

JRF evidence also suggests that the policy focus on prevention, identified as a strength by the Commission, has not achieved extensive progress in the form of preventative care delivery on the ground, even during an era of comparative financial ease (Raynes, *et al.*, 2006). Given the current budgetary restrictions it is likely that the care system will focus ever more exclusively on those with the most critical care needs and the demand for preventative and low-level services will systematically go unmet (Smith and Cavill, 2010).

JRF has just published a new report by the Centre for Policy on Ageing (2011) [How can local authorities with less money support better outcomes for older people? | Joseph Rowntree Foundation.](#)

This report updates previous research and the findings of a JRF Older People's Inquiry (Raynes, *et al.*, 2006) into 'that bit of help'. It shows that older people want and value low-level support – 'that bit of help' – but the benefits of investing in this are realised over many years, making it harder to prove impact and protect funding in the face of severe pressure on spending. JRF commissioned the report because evidence of the value to older people and to the public purse *does exist*, but it is widely dispersed. We wanted to mine the existing evidence base and bring to the fore several evaluated examples of imaginative, affordable

and effective ways of supporting older people's health, well-being, social engagement and independence.

Box 1: 'That bit of help'

'Well, it can be any kind of supporting service which can make a difference to our quality of life. Looking at the big picture we need support or services to help us to live an ordinary life. We need good housing; accessible, affordable transport; help for all the wee jobs at home which many of us are unable to do as we get older. It is no use having to sit at home and look around you and see jobs needing done which at one time you were able to do but now have no-one to do for you. Can you imagine how frustrated and depressed that can make you feel? Many need someone to go with them for shopping, doctor's appointments and other outside engagements and (unless there is a service in their own area to cover) that means that many older people would be stranded at home and become lost to society. Even in our own homes a few aids and adaptations can raise quality of life, our expectations and comfort levels. One cannot underestimate the difference to older people's quality of life that little bit of help makes. That bit of help and support that I need to contribute to the community and society means so much to me. I have been given back my independence and it has raised my quality of life and well-being.'

Nell McFadden, 2010

(A member of the JRF Older People's Inquiry 2005–06) cited in (CPA, 2011)

The report specifically highlights projects with some local authority involvement whether as lead commissioner, subsidiary partner, or through small grants or seed-funding. The projects (from both rural and urban areas and across the UK) demonstrate the importance of:

- involving people who use support and services in shaping them;
- investing in collective solutions, small grants or seed-funding for self-help groups, and developing local markets to provide what people want and value;
- refocusing towards the assistance that older people need and choose, and their experiences, and away from conventional social care and/or services;

- place-based approaches that reflect the whole of people's lives, and deliver value for money (e.g. by including transport, leisure, fire and rescue services to co-ordinate support).

Finally, JRF is concerned by the suggestion in the Call for Evidence that Attendance Allowance may not be considered as 'value for money', based on the fact that 29 per cent of those receiving it have neither informal nor formal care. This fails to recognise that AA can help people *prevent* the need for informal or formal care, in that it can be spent on healthier ageing, keeping warm and well, and being socially and mentally active. We would urge the Commission not to discount the value of such spending.

A funding system which can facilitate, support and *incentivise* investment in 'that bit of help' (especially by the NHS, local authorities and other agencies, but also by individuals themselves and communities) will be essential if the funding system is to be both *financially and socially sustainable* in the future, if it is to meet the *outcomes that people want and value* for a good life, and thereby reduce or delay the need for more costly support.

(Should the funding system focus narrowly on only those with the most critical needs or those receiving certain types of care or support associated with higher levels of support need, the Commissioners will need to assess how the reforms will tackle the current disincentives to local authority and other investment in 'that bit of help').

Personalisation

Older people and working-age disabled people are expecting, and demanding, to be more engaged with the planning and delivery of their care and support, and also to have more choice and options regarding their care (Mauger, *et al.*, 2010; Glynn, *et al.*, 2008). Latest JRF research findings from the Standards we Expect project demonstrates that there is a strong consensus among adult social care users (of all ages) that social care should be based on person-centred support. This means putting in place the support people need to live their lives on as equal terms as possible with non-service users. The research shows that care users want services to fit round them and their lives and relationships, as opposed to requiring them to fit into existing services. People want to be treated as individuals, to have providers listen to them, including the setting of goals and outcomes rather than techniques or procedures (Beresford, forthcoming). Other research highlights that the outcomes people want often extend beyond social care to include

health, housing, transport, employment, income and benefits, as well as maintaining and developing friendships and social relationships, a meaningful community life, and personal identity and self esteem (Godfrey, *et al.*, 2004; Raynes, *et al.*, 2006, Bowers, *et al.*, 2009; Blood 2010; Katz, *et al.*, forthcoming).

JRF supports the Commission's recognition of the drive for personalisation which (in policy more than in practice) has given people choice and control and the power to determine the outcomes they want. But the current funding system and levels of funding have been identified as major barriers to personalisation, independent living and empowerment (Beresford, *et al.*, forthcoming). The Commission must, therefore, ensure that sufficient resources are available, and that they can be used in ways which enable people to access the support they choose to achieve the outcomes they want (Beresford, *et al.*, forthcoming; Stone and Wood, 2010).

In relation to this, it is worth restating that several 'middle way' options now exist between residential care and domiciliary care, including extra care housing, supported living for younger adults, co-habitation and innovations such as 'shared lives' which are becoming increasingly popular (Burke 2010; Manthorp, 2010). These schemes look promising in promoting independence, quality of life and social well-being for those who cannot live wholly unsupported, but whose needs are not complex enough to require residential care (Callaghan, *et al.*, 2009; Bäumker, *et al.*, 2008). As such, the Commission must also consider how a funding scheme might support these increasingly popular 'middle way' options and the costs associated with them. Given the increasing variety of care and support settings now available, and that people may not choose from existing service settings, JRF would recommend that a new funding model was not based on the costs of a particular care setting or service type, as this is likely to date very quickly.

Complexity and partnership

The Commission rightly identifies complexity as a major shortcoming of the current system. A wide range of JRF-funded projects exploring service users' and carers' experience and perceptions of the care system identifies its complexity as a significant source of frustration and distress for people (Collins, 2007). Consultations with care users have shown that the current system of social care eligibility and its funding is opaque and confusing for those who need care and support, and multiple funding streams create confusing and sometimes irrational, overlapping ways of paying for care (Hirsch, 2006; Beresford 2010).

It is important for the Commission to acknowledge that the partnership between state and individual – identified by the Commission as one of the current system’s strengths – directly contributes to this complexity. It is very difficult to understand where the lines of responsibility are drawn between state, individual and family. A new funding settlement will need to present clearly how much people are expected to contribute (and when and how they make this contribution), what they will get in return, and what the state will provide. A minimum entitlement, or safety net for the poorest, will need to be explicit. A universal, effective information, advice and guidance system must be in place to support this.

The universality and effectiveness of any information and advice service will be vital for any funding system, but even more if it relies – to a lesser or greater degree – on individual voluntary contributions. This will depend on making people aware of the need to prepare financially for later life, and prepare to the extent likely to be necessary to secure a quality of life.

From ‘unmet need’ to outcomes

The Commission has highlighted the issue of unmet need as an area where there is limited evidence and which presents notoriously difficult challenges in terms of measuring, quantifying and costing unmet need. The Commission has asked for evidence to sit alongside the work on unmet need being undertaken by PSSRU.

Unmet need is difficult to measure. In an era of budgetary constraint, unmet need as a result of narrowing eligibility criteria will become more evident and measurable in so far as local authorities raise their Fair Access to Care Services (FACS) criteria, so those who have their support withdrawn are a clearly defined group with unmet needs. It is most likely that informal carers will attempt to meet this shortfall in formal care over the course of time, rendering these needs ‘met’, so’s to speak. The Commission recognises this phenomenon.

A focus on unmet need may lead to a vast underestimation of the level of funding required to meet the costs of care and support if the picture generated is one of numbers of hours of care and resources spent. Rather, it feels more important for the Commission to build a picture of the outcomes, and consider how to quantify and cost the resources required to meet those outcomes. This is needed if a care funding system is to deliver the *right amount* of funding, to resource the *right types* of services, which people *actually value*. Otherwise, defining need

as demand for existing services will mean a new funding system will fund 'more of the same'.

'Need' can and has been used in ways that compound stereotypes of passivity and dependence (Cordingley, *et al.*, 2001). This is a shortcoming in the funding system: care users report that it encourages dependency because people have to prove how *little they can do* to have any chance of qualifying for support. It contrasts with an approach based on independent living, where the qualification for support is that it enables people to live on as equal terms as possible as their non-disabled peers (Beresford, forthcoming).

JRF therefore suggests the Commission should take a radical and progressive move towards considering whether a funding system can support achievement of the outcomes that people want. This refocusing is, we believe, in keeping with the Commission's own core definition of care and support (see box 2).

Box 2: From the Dilnot Commission Call for Evidence

By care and support, we mean *all the things which help people stay active and independent, lead fulfilling lives, and build meaningful relationships*. Some support comes directly from government, but families and communities play an equally valuable role.

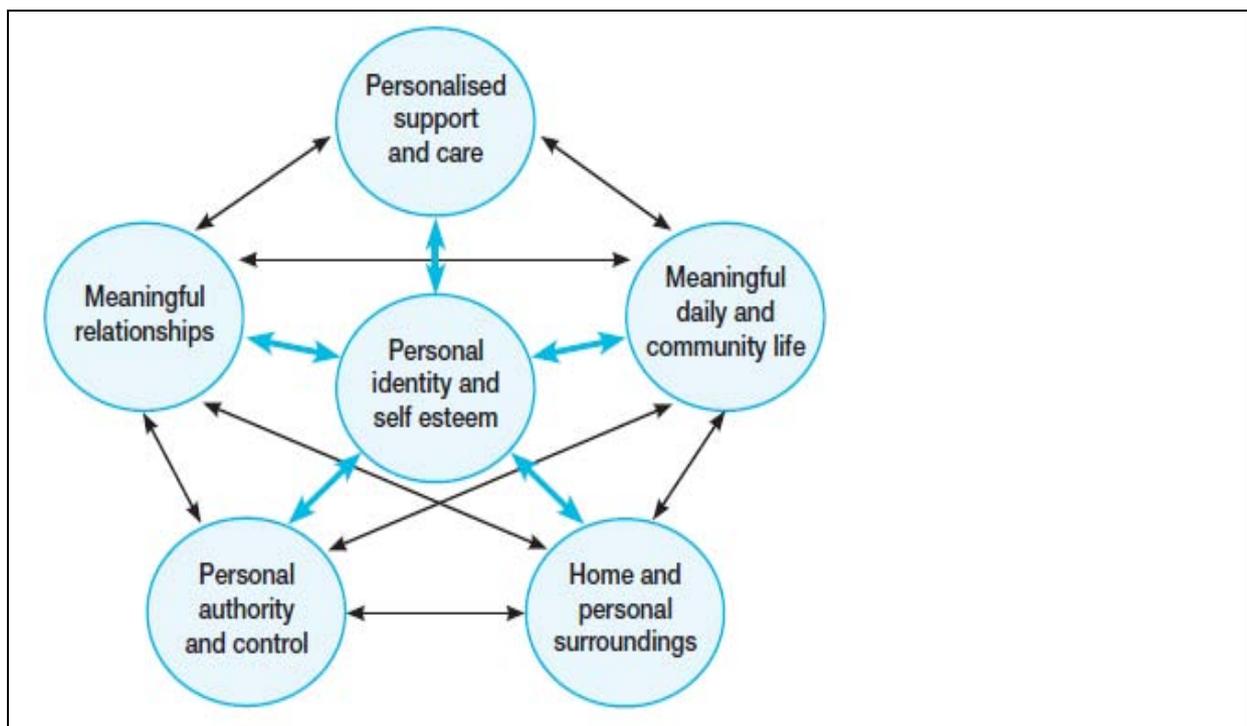
Care and support assists individuals with certain physical, cognitive or age-related conditions in carrying out *personal care or domestic routines*. It helps people *sustain involvement in work, education, learning, leisure and other social support systems*. It supports people in *building social relationships and participating fully in society*.

There is already a significant body of evidence about the outcomes that people have identified as important to them. Several studies have sought to identify a common set of outcomes that different care service users tend to want to achieve in different care settings. These outcomes are often wider than social care delivery and include health, housing, social and community life and relationships, and a sense of self-esteem and control (Godfrey, *et al.*, 2004; Raynes, *et al.*, 2006; Bowers, *et al.*, 2009; Blood, 2010; Katz, *et al.*, forthcoming).

A JRF study by the National Development Team for Inclusion (Bowers, *et al.*, 2009) found that the things most commonly mentioned by older people who live in care homes and who need a lot of support were:

- people knowing and caring about you;
- the importance of belonging, relationships and links with your local or chosen communities;
- being able to contribute (to family, social, community and communal life) and being valued for what you do;
- being treated as an equal and as an adult;
- respect for your routines and commitments;
- being able to choose how to spend your time – pursuing interests, dreams and goals – and who you spend your time with;
- having and retaining your own sense of self and personal identity – including expressing your views and feelings;
- feeling good about your surroundings, both shared and private;
- getting out and about.

Box 3: 'Keys to a Good Life' from Bowers *et al* (NDTi) 2009



Many people simply express the wish for an 'ordinary life', with 'sufficient' and secure income, social and intimate relationships, stimulating and interesting activities, accessible and timely information, support to manage things that pose difficulties, a comfortable, clean, safe environment, and a sense of belonging to, and participating in, communities and wider society (Godfrey, 2004). Few of these things, which are so highly prized, are included in the existing social and personal care delivery frameworks. As people's needs and expectations

change, it will be very difficult to establish whether these needs are being 'met' through pre-existing services.

The case study of Laura, a woman with HIV (see Box 4) is a pen portrait of how existing care and support services do not enable someone to achieve the outcomes she wants to achieve. In Laura's case, social services are not failing to deliver the basic care, but rather existing services are not enabling her to access the social and peer support she needs as a heterosexual woman with HIV.

Box 4: A pen portrait of care and support not delivering the outcomes people want to achieve – Laura, a woman with HIV

Laura, a mother of two children in their early 20s, had just entered into a new relationship in 2009 after a 'long and unhealthy marriage' when she became very ill. Feeling permanently exhausted and suffering from cystitis and thrush that would not clear up, she became alarmed when she spoke to a friend who had similar symptoms and had recently been diagnosed with HIV. Laura took the test, and both she and her new partner turned out to be positive. Her reaction, she says, was 'numbness and shock'. She insisted that her partner came with her to receive the results: *I felt that if he wasn't there he wouldn't believe me and he might run off and turn his back on the whole thing and not get diagnosed himself. It was very dramatic; he sort of fell to the ground and became hysterical, then wondered who I'd got it from and thought I'd passed it onto him which was absolutely [ridiculous]. I stayed very calm but was feeling furious.*

While Laura says that she generally feels 'optimistic', she is very concerned about staying strong and keeping her life 'in a better balance to stay healthy'. Working as a teacher, she earns a good salary at the moment, but worries about what will happen when her strength decreases more and more, as it has already begun to do:

I'm really feeling that it's wearing down now and it's very hard to maintain my professional life with so much turmoil going on in my personal life to do with my health. I get incredibly tired and I go to bed earlier than I used to and I would love to have a job where I started to work at midday and I'd be happy to work to mid evening but I don't, I work in education and I have to have an early start and I'm really, really struggling.

She also struggles emotionally: *[I feel] overwhelmed by my circumstances and the state of mind I was in that I made myself vulnerable to getting HIV, that I didn't take precautions, that I'm well-educated and a well-informed person and I started the relationship and used condoms and then without getting tested we stopped using them and that was a big mistake. I've had to question why I allowed that to happen. It's to do with guilt and how one is seen.*

Finding a support group that is tailored to her needs as a middle-aged, heterosexual woman is a major concern for Laura: *Given where I am demographically, that I'm in a minority and that the vast majority of people infected with HIV in the UK are black Africans and gay men so it feels as though services for heterosexual women, non-Africans are very difficult to access. I have been to events that the hospital has put on – of 20 people 1 or 2 are usually straight women in the group with mainly gay men. In an ideal world, I would like to go to a mixed group, culturally and [in terms of] sexuality.*

Laura feels that support groups especially for older people would also be much better suited to discussing and sharing the concerns specific to this group of people. Family planning, for example, is not a concern any more, but social care, the long-term effects of early experimental treatments on this 'pioneer generation', and sheltered housing are. Also, she says, 'there are so many issues to tackle particularly for people in their middle age because most people have quite ingrained habits, in terms of smoking or drinking or drugs or diet or exercise'.

It is not only peer support that she feels she is lacking, but also appropriate medical care and information on the interaction of HIV with other infections and conditions, such as the specifically female and middle-aged problem, the menopause: *I asked the consultant what could I do in terms of hot flushes and feeling exhausted and so on and could I continue with the herbal pills, and was quite shocked at his response which was 'I don't really know much about middle-aged women with HIV; my area of expertise is black Africans and the gay community.' I just found that so dismissive. Instead of saying 'That's not something I know a lot about and I will find out for you from gynaecological specialists' or 'I'll go and read up on it and get someone to find out something for you' rather than just cut me off. There are a lot of doors that are shut for people whose face doesn't fit.*

Yet she feels that it is especially people like her who need to be considered much more, in terms of both living with HIV and its

prevention: It's a rapidly increasing part of society, middle-aged men and women who come out of divorce or long-term relationships, haven't been dating since the 70s or 80s before HIV was on the map and have never thought of themselves as the kind of person who might get HIV and in that way are more vulnerable than ever.

From Power, et al., 2010: A national study of people ageing and HIV (50 Plus)

To clarify, we do not suggest that the Commission disregards existing models of unmet need, including the valuable work carried out by the PSSRU on unmet need. However, we do think the narrative regarding need ought to evolve – and that the Commission's recommendations and approach can support this evolution away from current deficit-based and service-based models towards more positive models of outcomes in line with personalisation and changing expectations.

This requires more emphasis on the care user to identify and articulate what they want, value and aspire to. Research suggests this can be challenging, in that people's demands are often influenced by the predominant social and cultural values of the time and can be subject to a person's expectations and experience of existing services. Current society engenders low expectations for self and others in old age, exacerbating this problem (Godfrey and Callaghan, 2000). Nonetheless, there may be room for a more balanced understanding of need *and want*, which combines both professional, service/demand-based definitions with a broader and richer picture of user-defined outcomes. It is only through considering what outcomes people want to achieve in life that the Commission can begin to address vital funding questions: How much do people need to fund their care and support? When do they need access to it? What should they be able spend it on?

Question 3: Given the problem we have articulated what are your suggestions for how the funding system should be reformed? How would these suggestions perform against our criteria that any system should be sustainable and resilient, fair, offer value for money, be easy to use and understand and offer choice? Please also take into account the impact that your suggestions will have on different groups.

The Commission has identified key priorities for reform – that people need to be protected from the risk of excessive and unexpected costs in later life; that there is a significant need for information and advice to improve people’s awareness of the system and the need to prepare for later life (though we would also add the need for advocacy, given that often the care system deals with the most vulnerable people in society and passive delivery of advice is not always adequate); and that there needs to be greater clarity between health, care and the welfare system. The fourth priority is most important: that increased resources – public, private and voluntary – will need to be dedicated to care and support in the future.

Suggestions for funding models

There are already several funding models, or elements that might be brought together into a single funding system, which are already on the table for consideration by the Commission. Over the years, JRF has commissioned work to consider or develop different ideas, and to weigh up funding options, including:

1. Private funding mechanisms for long-term care

Sandy Johnstone’s report (2005) on *Private funding mechanisms for long-term care* concluded that insurance plans designed to cater for the cost of care in later life have not been popular and most insurers have withdrawn. The report explores the low up-take of long-term care insurance products (despite market expectations) between 1995 and 2005. The findings remain pertinent given the lack of improvement in this area (as the Commission notes, it is now no longer possible to purchase new pre-funded long-term care insurance products in England). Some problems (lack of regulations or independent financial advice) can be remedied. The crux is whether any government will give sufficiently clear direction to consumers to highlight the need for them to plan into their old age; whether consumers will follow the government’s direction or continue to adopt an approach summed up as ‘to wait and see and to hope for the best’.

2. A social insurance model

The first JRF inquiry into *Meeting the costs of continuing care* (1996) recommended the adoption of a compulsory social insurance model, with payments made via a form of national care insurance. Thinking has evolved considerably since the 1990s, but the key element here is the notion of *risk pooling* which is absent in the current funding system. *Compulsory risk pooling* requires those who have the means to make some individual contribution to the cost of society’s future care needs.

Risks are difficult (increasingly so in rapidly changing times) to predict. Experience in other countries has demonstrated potential merits of social insurance-based systems which provide a level of universal entitlements to support (see Glendinning and Bell, 2008). As with other systems, these have had to evolve as the economic climate has worsened and as demand has increased.

3. *General taxation*

The Commission notes that many people mistakenly believe that social care is accessed on the same basis as health is accessed through the NHS. It is not surprising that general taxation remains a preferred funding option for many people (over and above the role already played by general taxation). This was confirmed through a small consultation organised by a national network of service users for JRF (Beresford, 2010) as well as the previous administration's Big Care Debate, where there was a clear message that delivery of personalisation is impeded by inadequate levels of funding and the contradictions created by the different funding systems underpinning the NHS and social care (Beresford, 2010). Setting political will aside, a prime concern is an unfair 'double whammy' where younger people contribute towards current care costs as well as towards future care costs. The possibility of *phasing in* a funding system based on general taxation or national insurance contributions merits full consideration.

4. *A Care Levy*

In 2010, JRF commissioned Philip Spiers and Donald Hirsch to set out ideas which would entail a *phasing in* over time – through a two-track 'care levy' where each generation pays its own costs. An initial charge on inheritance would be gradually replaced, over time, by funds built up through (for example) extra National Insurance payments levied on younger age cohorts. In addition to these two parts of the Care Levy, care would be funded partly through general taxation as at present and, potentially, through small charges to users. A broad sharing of costs among different generations – which takes into account also the differentials within generations (linked to ability to pay) could be presented as a fair settlement (Hirsch and Spiers, 2010).

JRF does not have a position on which of these or the many other models proposed by others is the right model. All have benefits and trade-offs. A hybrid model offers the potential to draw together the best elements – although the challenge will be to combine these into a coherent whole, which is simple to understand, with clarity about individual and state contributions, and about national entitlements.

Our primary interest is in ensuring that the criteria against which any reforms are judged reflect what we know from evidence, including the experience of people who use care and support, and people who provide informal care. JRF welcomes the Commission's commitment to considering *fairness* in the round, including: financial, intergenerational, gender, caring status and so on, as part of considering different funding systems for their capacity to be fair in the broadest sense. JRF also welcomes the criteria, many of which correlate to the six core principles identified by Hirsch (2006):

- *be fair and be seen to be fair* – both in the way money is raised and allocated;
- *support preventative measures* - through a system that encourages early intervention, rewarding rather than penalising measures that reduce the amount of care needed;
- *recognise the diversity of needs and allow recipients to retain their dignity* – through the care provided and resources left to individuals after paying for their care;
- *promote personal and family responsibility* – through an appropriate balance between family and state;
- *be sustainable* – by commanding general public support and by being responsive to demographic, medical, economic and other changes;
- *encourage a more efficient supply of care services* – by funding a range of care choices adequate to meet demand;

JRF also welcomes the reference throughout the Call for Evidence to achieving *quality outcomes*. From this standpoint, JRF has recently explored the potential for an outcomes-based funding model.

Towards an outcomes-based funding model

Is it possible to reform the current funding system in a way that actively supports, facilitates and incentivises the **achievement of outcomes** that people themselves want and value? Our thinking (Stone and Wood, 2010) resonates closely with the Commission's understanding of care and support (see Box 2 above) and with the Commission's emphasis on prevention and personalisation, including the power to determine outcomes.

We suggest that a funding settlement must start with an understanding of how people live their lives and what they want from later life – not from service-based assumptions based on services or settings (e.g. own

home, care home). As stated above (under ‘Personalisation’ and ‘Unmet need’), there is considerable evidence about what people want from life, expressed as outcomes. Service-led distinctions between (for example) social care and health do not resonate with how people live their lives, and cause confusion for users and practitioners (Beresford, 2010).

A funding model with the capacity to support and facilitate the achievement of outcomes has a number of benefits.

- Compatible with the existing care delivery system, which is increasingly focused in delivering outcomes as a fundamental element of personalisation, but which care users think is currently undermined by a lack of funding (Beresford, forthcoming).
- Outcomes-based commissioning is becoming more common (in policy, if not in practice) while outcomes-based assessments are now a central pillar of personal budgets.
- The Law Commission’s proposed new Social Care Statute is set to create a system based on needs and outcomes rather than service entitlements. A funding settlement based on old service-based assumptions would seem incongruous in such a context.
- A system which begins with an understanding of people’s lives, and resonates with their lived experiences, is likely to be publicly acceptable, and therefore sustainable, over the longer term.
- It is more likely to be adaptable and responsive to different needs, life experiences, lifestyles and expectations; resilient and responsive in the face of future change; and supportive of the human rights of care users regardless of ethnicity, gender and other differences as it removes any assumptions regarding what services people might want to use.

None of the main funding models on the table (e.g. the King’s Fund ‘partnership model’) *preclude* an outcomes approach. An outcomes-based funding model will need to define a set of outcomes which the public can expect as a minimum entitlement – either from the government as a safety net, or in return for a minimum contribution. Any funding model currently configured around a minimum entitlement to *services* could be adapted to allow for a minimum entitlement to *outcomes*.

Co-payment models are conducive, as the minimum entitlement could be designated as ‘state funded’, while the additional contribution made

by individuals could be reserved to achieve additional self-defined outcomes. This would of course mean that the poorest older people might have limited opportunity to set their own outcomes, as they would be reliant on the state-funded minimum entitlement. The design of that minimum entitlement would therefore be crucial, and should build on knowledge about what people want and value. The nature of an outcomes-based approach should mean that all individuals have greater opportunity to influence *how* those outcomes are met, thereby delivering greater choice and autonomy than would be the case with a minimum entitlement to a prescribed type of *service* or a prescribed type of setting.

Some form of insurance-based model would also work. Self-defined outcomes, and how they might be achieved, would be extremely variable. The range of costs is likely to be large. Therefore, a model which pooled the risks of some people requiring very costly support would offer a financially sustainable approach. The drawback of current insurance models is that they pay out on, and so the premiums are calculated on, the risk of needing services (e.g. residential care) and the cost of those services. Adapting this to calculate the risk and costs of outcomes would be a challenge, but both voluntary and compulsory insurance models are viable in this context, and could be combined with a care levy system (Hirsch and Spiers, 2010) to pay for the premiums in a way that is progressive and fair across generations.

Box 5: Additional questions against which to judge the funding reforms

1. How will the funding system *support and facilitate* people to achieve the outcomes they value and need for a meaningful and good quality of life?
2. How will the proposed reforms generate adequate funding for care and support, to enable delivery of *prevention, personalisation and choice*?
3. How will the funding system *incentivise* investment in low-level support or prevention? (Investment by individuals as well as by the state, local authorities, GP commissioners, private sector, voluntary sector, communities).

There are certainly distinct challenges to an outcomes-based approach, not least defining a minimum entitlement to outcomes, and calculating the costs of achieving those outcomes in order to quantify the costs to

the state and the individual. Nonetheless, aligning care funding to the delivery of outcomes rather than pre-defined service options is so important to the long-term success of a care funding model that JRF urges the Commission to consider the challenge carefully. Should the Commission wish to explore the potential for this approach in greater detail, we would be keen to contribute further (potentially commissioning new work).

Additional evidence relating to judging funding models

The Commission might also want to consider further the issues in the following papers (commissioned by JRF to stimulate debate on care funding):

- Can equity release help older home owners improve their quality of life? (Terry and Gibson, 2010)
- Identifying a fairer system for funding adult social care (Keen and Bell, 2009)
- Reducing gender inequalities to create a sustainable care system (Himmelweit and Land, 2008)
- Rethinking care and support: what can England learn from other countries (Glendinning and Bell, 2008)
- Duty and obligation: the invisible glue in services and support (Gandhi-Rhodes and Bowers, 2008)
- Care and support: a community responsibility? (Brindle, 2008)

Additional evidence

Length of stay in care homes

We have previously submitted evidence to the Commission on length of stay in three care homes run by the Joseph Rowntree Housing Trust. This confirms the picture drawn by the Commission of the wide variation in length of stay from a matter of weeks to (in some cases) well over a decade.

Demand for formal care services

In 2004, JRF commissioned the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Nuffield Community Care Studies Unit (NCCSU) at the University of Leicester to prepare updated projections of future expenditure on long-term care for older people in the UK to 2051 (Wittenburg, *et al.*, 2004). This supplemented existing data with new data (at the time) from the Government Actuary's Department which included greater increases in the numbers of older people and more optimistic assumptions about

future rises in life expectancy. While the analysis uses similar modelling to other PSSRU work which the Commission is already drawing on, the Commission might also consider the findings of this earlier analysis as some of the assumptions and variables will differ from later research. For example, the analysis considered three external factors that are important drivers of the demand for spending on long-term care: life expectancy, dependency and unit costs. The model defines dependency in terms of ability to perform personal care and domestic tasks. The analysis is based on prevalence of physical dependency, rather than of specific diseases. A further set of projections explored three scenarios: a decline in informal care; an increase in support for informal carers; and a change in the balance between residential and home care. These findings may therefore be of some use in supplementing the Commission's existing data (Wittenburg, *et al.*, 2004).

In 2006, JRF asked William Laing (Laing & Buisson) to estimate the cost of a range of policy changes and their impact on demand for formal care. This included extending free personal care in care homes and introducing a constant 33 per cent rate of co-payment, shared between individuals and the state for all long-term care services. The findings were brought together in a summary and report (Hirsch, 2006). The data behind the calculations is available in an Excel spreadsheet at <http://www.jrf.org.uk/publications/paying-long-term-care-moving-forward>

Housing and care and support

JRF has been asked to draw on our work on this area to consider older people's housing and assets, and in particular the issue of downsizing, as well as the provision of housing with care and support more generally.

Housing and equity in later life

There are estimated to be around 1 million older people currently termed 'asset rich and income poor', with housing assets of over £100,000 but whose income is low enough for them to be eligible for means-tested benefits. This lack of income often means housing repairs and adaptation go unmade, quality of life is poorer as food and heating bills are too high, and care and support services in the home cannot be afforded. Disagreement over how to account for housing assets in care eligibility, without requiring someone to sell their home in order to pay for care, has proved to be an emotive debate and one possible reason why the care funding system has remained unreformed for so long (Keen, 2008).

One consequence of the current system is that ‘asset rich, income poor’ older people cannot pay for care in their home or certain home repairs or adaptations without selling their home to release funds. However, there are options open to older people to access their housing equity without selling up. JRF has already brought to the Commission’s attention the work of the JRF Task Force on Equity Release (Terry and Gibson, 2010) and the three pilots of an affordable equity release scheme. The Home Cash Plan (offered by Just Retirement Solutions) in three local authorities (Royal Borough of Kensington and Chelsea, London Borough of Islington and Maidstone) has been designed specifically for older people who have little income but some assets which they could use to fund care in the home, or purchase ‘that bit of help’. The product allows home-owners to draw down smaller amounts than mainstream equity release products, so that the money received does not affect the client’s Pension Credit or other benefits eligibility. The pilots have a further six months to run. It is important to stress that equity release is not and will not be suitable for everyone.

Downsizing

The most common way of accessing housing assets among older people is to downsize. JRF funded a study by the Resources in Later Life (RILL) team at Loughborough University which found that older people downsize for a number of reasons. Being able to release housing capital by moving to a cheaper property or renting is one reason. Other reasons are being able to move to a more manageable, easily maintained, accessible or more conveniently located property. Although a suitable home environment can be crucial to independence, health and well-being in later life, older householders (aged 60 years plus) are more likely than average to live in non-decent and energy inefficient homes. Living in a decent and suitable home can therefore entail moving house. The study found that house moves were often considered in response to bereavement, worsening health, or the need to be closer to key services or family members. As a result, moving in later life was often associated with times of distress and uncertainty (Hill and Sutton, 2010).

The research team, in interviewing 78 older people who were thinking of moving or about to move, identified the following factors as helpful, and which enabled people to move in a relatively stress-free way:

- having a friend or family to help;
- physical health – although participants had a range of health conditions, those who moved were still mobile and better able to manage the practical aspects;

- clearing out a lifetime of possessions was emotionally as well as physically exhausting. Seeing a move as a fresh start, buying new things and decorating helped people cope with upheaval and loss of continuity, familiarity and place;
- being able to leave furniture behind for the incoming purchaser; and
- staggering a move: having the new property available before moving out of the old one enabled a gradual move, although financially this could be hard.

The team identified a range of practical, emotional and strategic obstacles which could contribute to people feeling either unable, or unwilling to move:

- Availability of a suitable property was a key issue. This included long waiting lists for rented warden-controlled properties. Home-owners mentioned the lack of affordability of bungalows and limited supply of owner-occupier property suitable for older people. Some just did not like the idea of renting.
- Moving was seen as too daunting. Even where people recognised that living in a more manageable property made sense, they were put off by the upheaval, having to sort everything out, physically packing, emotional ties to their home, not knowing where to move to or how to get the process started.
- There was a resistance to living in properties specifically designed for older people. Occasionally participants mentioned psychological barriers associated with living among 'old people', fearing it would make them feel older themselves and this was seen as a last resort.

Based on these findings, the researchers concluded that:

- Better information and advice on available suitable properties was needed, and advice on the selling process, so that older people knew 'where to start'.
- Efforts to dispel myths about older people's housing would be important. People who had moved to supported living were positive about this and recognised there was often a gap between their perceptions and realities.
- Practical support services to help older people deal with estate agents, have transport to view properties and do the packing

was important (and beyond what standard removal companies could offer).

Future generations of older people may not have such an imbalance of income and assets, and so the need to downsize or release equity with a financial product in order to pay for care and support may not be such a pressing issue in years to come.

Housing with care/extra-care housing schemes

The quality and suitability of an older person's home has a significant impact on their mental and physical health and well-being. A suitably adapted, conveniently located home can make all the difference to an older person's sense of social inclusion and independence, and can certainly delay, if not remove altogether, the need to move into residential care settings. The findings of the HAPPI report (www.homesandcommunities.co.uk/housing-ageing-population-panel-innovation.htm) published in January 2010, gives a clear picture of what can be, and has been, achieved in the UK and in other countries in terms of innovative and cost-effective ways of building sustainable and inclusive homes and communities for an ageing population. It includes a case study of Hartrigg Oaks, a continuing care retirement community built and run by JRHT in York.

Demographic change combined with breakthroughs in technology and medical treatment means there are increasing numbers of older people living alone, and increasing numbers with higher support needs (Blood, 2010; Falkingham, *et al.*, 2010). Such groups may require levels of support that cannot be effectively delivered in an individual's home, or they may find social inclusion and community life is better delivered in communal settings. As policies focus on enabling older people to remain at home, there is a risk that less attention will be paid to the experiences of this large and growing group of people who may benefit from communal care settings.

Recent years have seen a continuing shift towards a wider range of options which combine care and support with housing in ways that can meet different needs – including the need for meaningful relationships and participation in social life.

JRF research and JRHT practice (as a provider of extra-care housing schemes, such as Hartfields in Hartlepool) demonstrates that when properly planned and run, extra-care housing schemes can promote independence, healthier ageing and social inclusion among the older

residents and the surrounding community (Croucher and Bevan, 2010; Callaghan, Netten and Darton, 2009). Characteristics of successful extra care schemes include:

- the availability of communal facilities and a diverse range of organised activities to help residents interact;
- opportunities for residents themselves to run and organise their own activities and remain engaged in their own governance;
- adequate staff time and resources to support social activities;
- the presence of GPs and specialist nurses on site;
- the strategic location of extra care schemes, integrating into communities rather than building ghettos in peripheral locations;
- the increased use of mixed tenure to enable older people to buy or rent in the schemes, and the presence of general needs housing within or nearby, so that families and carers can live nearby (Burke ,2010).

However, extra care schemes can raise particular challenges for some groups, including older people with high support needs (Garwood, 2010) and they can prove costly. In a small cost-effectiveness study looking at a particular scheme in Bradford (Rowanberries), researchers found that living in extra care *did* support residents to achieve the outcomes they valued and improved their quality of life, but the living arrangements were more expensive than where residents had been living previously (Baumker, *et al.*, 2008). This is a single study and the findings of the forthcoming PSSRU evaluation of extra-care housing schemes should provide a much stronger evidence base. Nonetheless, the study reminds us that weighing up the cost-benefits of a given care option is a value-driven exercise, in that relative value must be placed on improving people's quality of life and achieving the outcomes that matter to them. This reiterates the point made in the main body of our submission above: that the 'what' and the 'how' of care funding cannot easily be separated. If, hypothetically, extra care became the 'norm', as the most popular form of care which every older person wanted to move in to (and were prepared to pay for), then the Commission would have to consider the additional costs associated with this and how a funding system could be created to enable people to access this form of support as a means of achieving the outcomes they value.

As noted above Shared Lives (www.naaps.org.uk/en/shared-lives-membership/?PHPSESSID=63c6674093086a07f31a2078abcb7280) and co-housing also represent innovative approaches, with the former

providing older people a home with a carer's family – and thereby providing home care plus a family life and social contact for the older person, while the latter creates a 'mini neighbourhood' where older people retain their independence and autonomy but find companionship and support on their doorsteps. This could prove a valuable alternative for those who are reluctant to join one of the more traditional options available to older people, but who do not relish living alone (Manthorp, 2010; Burke, 2010).

Although many more 'middle way' options are becoming available, this does not mean traditional residential and nursing care settings are now redundant. For increasing numbers of older people with the highest support needs, such services will remain invaluable.

In relation to the Commission's work, the challenge is to start from people's lives and their (changing) expectations, and seek to support the outcomes they want to achieve and are prepared to contribute towards. The system must not presuppose one or other particular form of care or housing/care as the favoured way.

Nursing and residential care

JRF research shows that both the quality of care and the quality of life in traditional nursing and residential settings could be improved (Bowers, *et al.*, 2009; Universities of Warwick, West England and York, 2008). In particular, care home residents often experience a lack of choice, control and opportunities to express opinion and be involved in care delivery. Care homes are not easy places to express personal feelings, and older people living in supported environments need a much greater variety of ways to both contribute and express themselves. Above all, they need encouragement and support to do so, and a right to self-expression as a clear indicator that they are valued and equal citizens (Bowers, *et al.*, 2009).

Given the lack of engagement and control among those with high support needs in these settings, there is a risk that residents will be excluded from the reforms and improvements being made to the care system more broadly. They may well be left behind as personalisation, autonomy and choice and an outcomes focus is implemented elsewhere for other groups to enjoy. (People in residential care have only recently become eligible for Personal Budgets, where previously they were ineligible for Direct Payments).

The Commission is right to work towards a funding system that does not discriminate against specific populations or groups. This needs to include people living in a particular care setting. Value for money, fairness and choice in funding options can be more challenging to achieve in residential and nursing home settings, and as such it falls within the Commission's remit to ensure older people with high support needs – a group rapidly increasing in size and diversity (Blood and Bamford, 2010) – are treated fairly and equally compared to other care users, and enjoy the same opportunities for empowerment and influence over the care and support they receive. This will require effective training to deal with the newly emerging needs of an ageing population, including older people with both learning disabilities and dementia (Watchman, *et al.*, 2010) and HIV (Power, *et al.*, 2010), as well as innovative (and often low tech) ways of enabling older people to communicate with care workers and express their opinions (Murphy, *et al.*, 2010).

Conclusion

We urge the Commission to take a radical and progressive approach, recognising the inextricable links between funding and delivery, and assessing proposed funding reforms against the following questions (in addition to the Commission's existing criteria):

1. How will the funding system *support and facilitate* people to achieve the outcomes they value and need for a meaningful and good quality of life?
2. How will the proposed reforms generate adequate funding for care and support, to enable delivery of *prevention, personalisation and choice*?
3. How will the funding system *incentivise* investment in low-level support or prevention? (Investment by individuals as well as by the state, local authorities, GP commissioners, private sector, voluntary sector, communities).

Our response has drawn on JRF research evidence – much of which has drawn directly on the experiences of people using care and support, and aspiring to lead an 'ordinary life' or a 'good life'. Our response has also highlighted the significance of the growing diversity of the population, the need for a funding system to keep pace with changing expectations for a good life, and the importance of looking beyond conventional social care services to consider (in particular) housing and evolving ways of integrating housing, care and support.

At a time of budgetary constraints, we also urge the Commission to acknowledge the potentially negative impact that under-investment and inadequate funding for social care may have over the next four years – putting at risk the successful implementation of a reformed funding system in the next parliament.

JRF and JRHT are committed to advocating for a radically reformed funding system that is fit for current and future generations. We will be delighted to provide further information on any of the points raised in the response, or on the additional material cited below.

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