
The Resolution Foundation Written Response to *Shaping the Future of Care Together*

SUMMARY

The Resolution Foundation is an independent research and policy organisation whose goal is to improve the wellbeing of *low earners*, that is, those with a below median income who are broadly independent of state support.

We welcome the broad thrust of the Green Paper. We believe the shift towards seeing care as a universal entitlement rather than a safety net will vastly improve the experience of many low earners who often find themselves *squeezed* by the current system:

- 78 per cent of low earners over the age of 65 own their home outright, and so are likely to have assets which will make them ineligible for state-funded social care
- 45 per cent of low earners have made no provision to pay for their care, and 68 per cent of low earners feel that care is becoming less affordable
- Some of tomorrow's low earning older people are today's carers: low earners are 25 per cent more likely than average to be providing some form of informal care

Our view is that further work is needed to clarify the terms of the 'universal entitlement' before a lasting funding settlement can be agreed. From the perspective of low earners, further detail is needed on the funding options before they can be assessed against fairness and affordability criteria. It is also unlikely that any single funding model proposed in the Green Paper will provide the full solution to increased demand for social care. Rather, government needs to think about:

- How to secure additional *collective* funds for care and support, through innovation, efficiency, redirecting funds from other activities and reforming the tax and national insurance systems
- How to stimulate a market that will incentivise greater contributions directly by individuals. We believe that this will require a *mixed market* solution of both state-sponsored and privately provided products. This diversity is necessary to meet individuals' needs, resources, attitudes to risk and inclinations to plan, and to ensure people are also able to cover accommodation costs and low level care needs
- How to plan a reform process that takes a *staged approach* to a funding settlement, where new approaches are introduced over time to meet the needs of different generations at different life stages.

We also argue in this response that more work is now needed on planning the route to reform. This will require greater alignment between funding options and a reformed delivery model, as well as a more explicit focus on what a successful reform process might look like. It will also require momentum to be maintained on the *immediate reform agenda* as we continue to work towards a long-term settlement. In particular, enabling the market for social care to work effectively is vital to improving outcomes for older people, and for delivering a vision of choice and personalisation. We therefore welcome the Green Paper proposals around a national information and advice service, and an entitlement to a needs assessment. Our response offers further thoughts on how this could work effectively.

INTRODUCTION: LOW EARNERS AND THE LONG TERM CARE SYSTEM

1. The Resolution Foundation welcomes the opportunity to respond to the recent Green Paper, *Shaping the Future of Social Care*. We are an independent research and policy organisation whose goal is to improve the wellbeing of *low earners*, that is, those with a below median income who are broadly independent of state support. We do this by undertaking research and economic analysis, developing practical and effective policy proposals and engaging with policy makers to bring about change.
2. We have been working to improve outcomes for low earners in the long-term care system since 2008. To inform this work we conducted a series of focus groups and some polling in collaboration with Deloitte in early 2008, and ran a number of workshops in autumn 2008. We have recently updated this work through a series of in-depth interviews with low earners who are self-funding their own care. We have attached summaries of these interviews at Annex A, and all of the research described here informs this response. We have published our findings in a range of reports and discussion papers all of which can be found on our [website](#). These include:
 - *Lost: low earners and the elderly care market* (February 2008)
 - *A-Z: mapping long term care markets* (April 2008)
 - *Navigating the Way: the future care and wellbeing of older people* (December 2008)
 - *Innovation and Efficiency in Long-Term Care* (December 2008)
 - *Local Market Shaping* (December 2008)
 - *Facilitating Increases in Long Term Care Funding* (December 2008)
 - *Home Equity: accumulation and decumulation through the life cycle* (forthcoming, 2009)
 - *Funding Future Care Need: the role of councils in supporting individuals to access the capital in their homes* (forthcoming, 2009)
3. Our analysis shows that:
 - There are 4.9 million retired low earners across the UK¹ and they are two times more likely than the UK average to be care users²
 - 78 per cent of low earners over the age of 65 own their home outright, and so are likely to have assets which will make them ineligible for state-funded social care
 - 45 per cent of low earners have made no provision to pay for their care, and 68 per cent of low earners feel that care is becoming less affordable³
 - Some of tomorrow's low earning older people are today's carers: low earners are 25 per cent more likely than average to be providing some form of informal care⁴

¹ Resolution Foundation, *Closer to Crisis? How low earners are coping in the recession* (November 2009)

² Resolution Foundation, *Lost: low earners and the elderly care market* (February 2008)

³ *Lost*, *ibid.*

⁴ *Lost*, *ibid.*

4. In this context, long-term care presents particular challenges for low earners. They are on the **'cliff-edge' of means testing eligibility**: the majority are not eligible for free or subsidised state care, and yet their low incomes make care costs a significant financial burden. This group are likely to spend a larger proportion of their weekly budgets on care than both higher and lower earners. In other words, low earners are squeezed by virtue of the *mixed economy* that characterises the funding and delivery of social care.

5. Our polling work with low earners in the care system shows that this group does not have a positive view of the system as it currently stands. 75 per cent of low earners believe that social care should be seen to be as important as the National Health Service – but at the moment they **perceive that the system is unfair**, punishing those who work and save to prepare for old age:

"I'm beginning to think we were very foolish to have struggled and bought our own house...you don't get any help from anybody. And people who have wasted their money, they get everything given to them"

6. They believe that care is **declining in quality and becoming less affordable**. These perceptions come from their 'squeezed' position: too rich to qualify for state-funded care, and too poor to have the resources to invest in commercial products designed to help people plan and pay for their care.

7. In addition, low earners report that they **struggle to navigate the system** and understand what they are entitled to, or what choices they have. Qualitative research conducted by the Resolution Foundation highlighted how people felt they had to *'do all the chasing'* in order to get information and *'fight'* to access services. These perceived hurdles are seen by low earners as a means to ration services and are considered unfair in this light.

8. That said, our research provides some important insights about low earner attitudes towards how care is paid for. Low earners have a strong sense of **fairness** and in this context they accept the concept of means testing. However the inclusion of the family home as part of the means test is seen by low earners to penalise those who have sought to look after themselves and live independently of state support throughout their lives.

"If I pay half, the government pays half, as long as I've got enough funds."

"I think we should perhaps be asked to pay a reasonable cost, but not this exorbitant charge... 50/50 would be ideal"

9. When it comes to paying for social care, low earners accept the need to individuals to make some kind of contribution. As a group they are generally **supportive of funding models that are about 'giving something back'**. Our polling showed that three quarters of low earners (compared to 71 per cent on average) would pay an extra penny in the pound on income tax to raise funding and quality. And just under half (48 per cent) support the idea of compulsory contributory schemes so that individuals and government pay for care together.

“I think its unfair that we have to pay so much income tax on our state pension when we have a small private pension [...] I think we are taxed far too heavily on our pensions, if they would ease on that, we could help ourselves with our care.”

10. Perhaps unsurprisingly given their increased likelihood to be doing some kind of informal care, low earners believe **government should be doing more to support carers**, either through direct financial support or through respite care. Low earners see carers as saving the government money by reducing people’s reliance on formal care and on residential services.
11. Finally low earners in our research emphasised the importance of **consistency in what is funded where** – between different parts of the country and even within single local authorities.

SECTION 1: overview – the reform of social care

13. We welcome the publication of the Green Paper but fear it will not generate the breakthrough in social care reform that many were hoping for. There is no question that there has been considerable progress and improvement in recent years, but it has been patchy and not of the scale required to meet the challenge of delivering the right quantity of quality care to an ageing population in coming years.
14. In our view this breakthrough will not be achieved unless greater attention is paid to two overarching issues, as well as getting the detail right: first, greater clarity about what we mean by a ‘universal offer’ in social care, and what aspects of the current mixed economy of care services should be available for free and to whom; and second, the route to reform itself. It is only through focusing on these issues that the questions asked in the Green Paper about funding can be fully addressed.

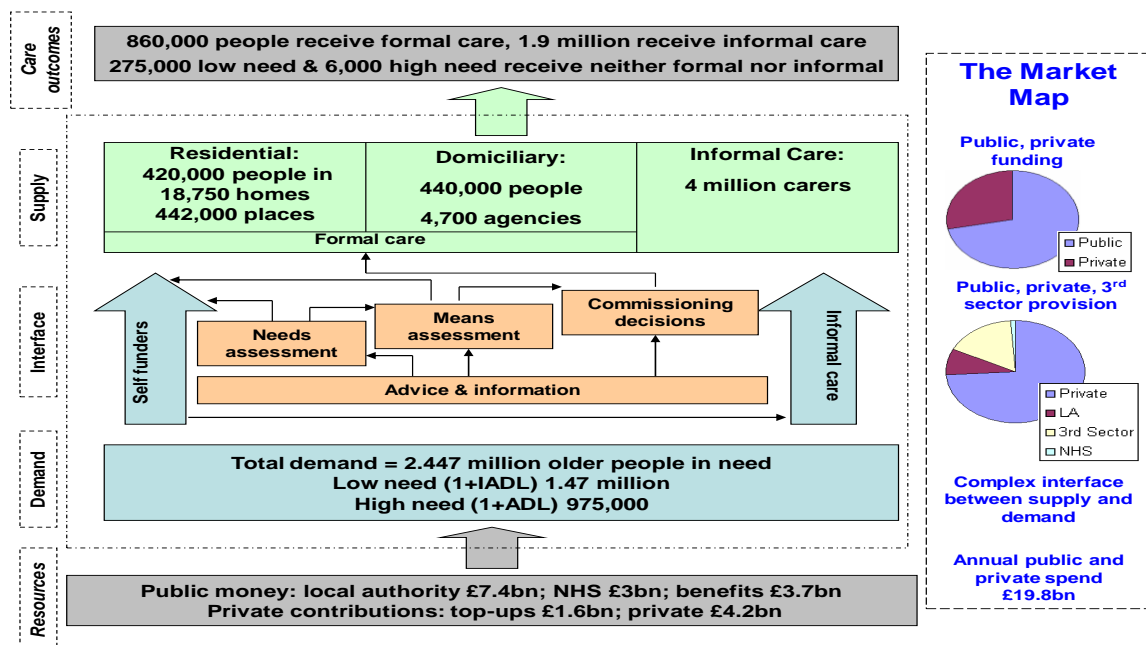
Social care: a mixed market for a social good

15. At its highest level, long-term care functions as a market, with defined demand for care (based on need) and formal supply (residential and domiciliary care). Care is also a social good, which the government has a duty to provide for those in need if they cannot afford it themselves. As such it does not operate as a ‘pure’ private market – its efficiency must be balanced with progressive and redistributive characteristics.
16. There is a mixed economy in terms of the funding of social care as well as its supply. Public and private funding is used to purchase care from private, public and third sector suppliers. A sizeable ‘grey’ economy of informal care operates alongside this mixed market.
17. Compared to ‘pure’ markets, the market for care is complicated, with an array of intermediary bodies and practices that create a complex interface between supply and demand – for example, needs and means testing, eligibility criteria, as well as local authority commissioning practices. Furthermore, supply and demand are weak: for example, people requiring care are not empowered consumers, with care often being a ‘distressed’ purchase. Similarly, providers are constrained in their ability to innovate by regulations, contractual requirements and the sometimes distorting effects of council block purchasing.
18. Finally, the mixed market of care has a geographical dimension that adds to its complexity. Social care is arguably a collection of highly diverse local markets rather than a unified whole, with differences in supply, eligibility criteria and costs.
19. We have reproduced a diagram of the mixed market of social care that we developed for our report *A-Z: mapping long term care markets*⁵. It illustrates

⁵ Resolution Foundation, *A-Z: mapping long term care markets* (April 2008)

some important points that should inform debates about the funding and the reform of social care:

- There is already a significant amount of ‘unmet’ need in the system – 275,000 low need and 6,000 high need people do not receive any kind of care, formal or informal.
- Even when informal care contributions are excluded, private contributions to paying for social care already makes up a significant proportion of funding total care - £5.8 billion of private money compared to £7.4 billion of local authority funding.
- The ‘market’ for social care extends well beyond that care which is either paid for or delivered by public bodies – it includes informal care, self-funders who privately purchase their care, and families who ‘top-up’ state-funded care.
- The spectrum of demand for care is broad: while some people may only need their shopping done for them once a week, others will need 24 hour care in a residential setting.



20. It is essential that any debates about funding social care start with a consideration of how the current system looks from the perspective of its users. We are particularly interested in how it looks from the perspective of low earners. Our research shows that:

- It is seen as a complex system. While low earners understand in broad terms the difference between social care and health, they are confused about the terms of means and needs-testing, variations in eligibility, and this leads to a sense that they have to fight to get their needs met, and that the current system creates barriers to people accessing services to which they are entitled.

- It is seen as an unfair system. Low earners feel the current system penalises those people who have worked hard and planned for their old age.

“What the government does is make us poor before they help”

- It is seen as an expensive system. Low earners are on the cliff edge of eligibility: nearly three quarters of them have too many assets to qualify for state support (usually in the form of housing), and yet their relatively low incomes makes paying for their costs a significant financial burden.⁶

21. Our view is that the Green Paper has not sufficiently clarified the roles and expectations of the state, families and individuals in relation to care. Over the years, social care has been defined and redefined and many of the more recent government publications, including the Green Paper, talk about state-provided care and support as a *universal offer* or a *citizenship entitlement*, rather than as a more limited safety net.⁷ At this juncture, it remains unclear what forms of support, and what level of care (if any) form part of any settlement covered by the funding options set out in the Green Paper.

22. In other words, the concept of a ‘universal offer’ is gaining currency but it remains unclear what this constitutes. The Green Paper outlines some of the potential components of the offer – including access to information, advice and guidance, needs and means assessments, and varying levels of financial support – but the lack of a clearer statement of the offer, coupled with insufficient modelling of the costs of each of the funding models, makes it extremely difficult to assess which of the options put forward in the Green Paper is the most sustainable or fair.

23. Furthermore we question whether any single funding option can provide the solution in isolation. Our view is that any long-term and sustainable funding settlement will require a *range* of options for individuals and society to pool the risks associated with paying for care. This is all the more the case given the scale of demographic change in this country. Additional funding will be required simply to stand still, let alone to broaden the scope of what counts in publicly funded care services.

24. Despite these issues, we remain hopeful that the underlying shift of the Green Paper – of seeing some aspects of care as a universal entitlement rather than as a safety net – will vastly improve the experience of many low earners. For all those people who are either self-funding or part self-funding their care, the Green Paper’s commitments to offering support in the form of better advice, more consistent needs and means testing, and an improved market for both care and products to save for care are potentially a very positive development.

The route to reform

25. Social care urgently needs an enduring and sustainable settlement and this must be the singular goal of politicians, policy makers and practitioners. Our concern is

⁶ For more in-depth analysis please see Resolution Foundation, *Navigating the Way: the future care and wellbeing of older people* (December 2008)

⁷ see for example Putting People First; Building a Society for All Ages (DWP 2009)

that insufficient attention has been paid to the *process* by which lasting reform is achieved. Evidence from elsewhere underlines the importance of a carefully orchestrated process of reform that builds consensus, maintains momentum and engages in evidence-based debate. There may be valuable lessons to be learnt from successful reform processes – for example, the recent pensions debates show the value of:

- An overt recognition that achieving cross-party political consensus is essential in achieving radical political reform
- An investment in high-quality, timely and independent analysis. This shaped the entire pensions reform process; in contrast we have been disappointed that the LSE analysis anticipated to support the Green Paper has now been delayed until 2010
- A clear conceptual framework and agreed terminology. Even if there was not always full agreement about the issues in pensions reform, people had some common ground from which to debate the issues

26. We believe that despite good progress in social care debates, we still lack the political consensus, public debate, and evidence base that will be necessary for lasting and sustainable reform.

27. For example, recent announcements about the provision of free care⁸ have clouded the debate about what a 'national minimum entitlement' might or should contain. Clarifying what, as a society, we wish to pay for collectively when it comes to caring for older people will require further debate: it will not be solved by technical analysis alone.

28. Similarly the Green Paper asks about the appropriate balance between national and local control. There is not an easy answer to the question of which agents should be responsible for each element of the new architecture. Resolution will depend on a *political* decision about whether, as a society, we prioritise local control and flexibility over national consistency.

29. We have previously argued that the same tests that were applied to pensions reform could usefully be applied to social care reform. The five tests are:

- Does reform promote personal responsibility, giving everyone the opportunity to lead a fulfilled life in old age?
- Is it fair, to women and carers and to those who have saved, and does it protect the poorest?
- Is it affordable to tax payers and the economy as a whole?
- Is it simple, clearly setting out what the state will do and what is expected of citizens themselves?
- Is it sustainable, with the reform package forming the basis of an enduring national consensus?

⁸ See Gordon Brown's speech to the Labour Party conference, September 2009
<http://www.communitycare.co.uk/Articles/2009/09/29/112722/gordon-brown-makes-free-personal-care-pledge.htm>

30. Finally we believe that the route to reform must encompass both funding *and* delivery: the two issues are intertwined and more work is needed to align them. The remainder of our response outlines our reflections on both delivery and on funding. While we believe more work is needed to clarify the vision and long-term goals for social care, we also believe that there are a number of steps that can be taken now to improve outcomes for all care users and their carers.

SECTION 2: REFORM OF THE SYSTEM

Question 1: We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- Prevention services**
- National assessment**
- A joined-up service**
- Information and advice**
- Personalised care and support**
- Fair funding**

**Is there anything missing from this approach?
How should this work?**

Question 2: We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- Do you agree?**
- What would this look like in practice?**
- What are the barriers to making this happen?**

31. We welcome many of the proposals contained in the Green Paper. In particular we welcome the following commitments, and in this section we reiterate the key principles we believe should underpin the changes proposed in the Green Paper:

- Clear national framework with a national minimum entitlement
- National assessment
- New strategic market shaping role for local authorities
- Care navigation service available to all

Clear national framework

32. Our research exploring low earners' perceptions and experiences of the care system shows that they find it unfair and confusing. We identified serious information asymmetries which leave the care user in a weak position. We therefore welcome the Green Paper's commitment to a new national minimum entitlement that will end the current confusion experienced by low earners. It should alleviate their concerns about the 'unfairness' of the current system, which are borne out of a lack of clarity regarding entitlements and responsibilities of the individual and the family.

33. However getting this entitlement right, and making it transparent, is crucial. It will not be an easy task to accomplish and government should not underestimate how much work is required to achieve this from the current situation.

34. We agree that needs eligibility should be set at a national level (i.e. the equivalent of critical, substantial, moderate or low). However local councils should still have the flexibility to set their own monetary values for different levels of eligibility

(increasingly in a transparent way thanks to personal budgets) to reflect the costs of labour and other local variations that may need to be taken into consideration.

35. The *level* at which needs eligibility is set is as important as who sets it. We believe this is fundamentally a political decision that should reflect the government's ambitions for how older people and society are treated in the future, the priority given to preventative care, and the available resources for care funding as weighed up against other priorities.
36. We have argued that a minimum entitlement of care should be made to both older people and their carers. We believe it should be part of a clear national framework for care, which would also include:
 - A national regulatory framework
 - Clear delegation of key functions to appropriate agents
 - Greater clarity in the respective roles of individuals, families and the state
 - A national set of eligibility criteria for state contributions⁹

National assessment

37. We welcome the commitment to a national, portable assessment of needs, which we believe will help low earners predict whether they will have to contribute to their care costs and prepare accordingly.
38. In the past we have argued that a care and wellbeing assessment should be part of any national minimum entitlement for everyone over 65 and their carers. We argued that this should be divorced from questions about eligibility for state funding, thus tackling problems with the current system that often conflates people's needs with their means. This conflation has led to a situation whereby those people deemed ineligible from a financial perspective do not access a needs assessment: a CSCI study found that nearly half of self-funders surveyed did not have such an assessment.¹⁰
39. For low earners, who need support and should have access to a needs assessment even if they end up self-funding, this conflation can be problematic.
40. Earlier Resolution Foundation work on this issue argued that a universal care and wellbeing assessment should be a comprehensive assessment of a person's health, care, social, financial and other needs related to their wellbeing. Our view is that divorcing this wellbeing assessment from means-testing will enable a more interactive process which is focused on the entire spectrum of issues – including for example finances, preventative action around diet and exercise, everyday activities such as shopping and companionship – as well as more formal care provision.
41. We believe that this needs assessment should not be a one-off: rather, people should be approached at key life-stages, to reflect the fact that needs change over time. The focus should be on prevention, but it could also be used at the

⁹ For more in depth analysis please see *Navigating the Way*, *ibid*.

¹⁰ CSCI, *A Fair Contract with Older People?* (2008)

point of needing care. This kind of assessment should help individuals to better understand their own needs and access the support which will most help them. Such assessments will also help to raise the profile of the importance of planning and preparing for care in older age.

42. We also believe that these assessments should be extended to any carers involved in delivering a person's care. The needs of carers are overlooked in the current system, and their needs ought to be assessed alongside the older person they care for in order to consider the full range of options that will work.

Market shaping role

43. We agree with the Green Paper that local councils have a key role to play in providing a wider range of services in care and support, as well as better quality and more innovative services. Our view is that the local authority role should not only be to address market failure but also to pro-actively shape local markets for care. They need to build their capacity to provide strategic oversight of local care markets. And they need to work behind the scenes to facilitate and encourage this market, help providers to respond to consumer feedback, and to offer flexible, affordable and good quality services.

44. Previous work by the Resolution Foundation identified the tools that a market shaping organisation would require to ensure sufficient volume, diversity, quality and affordability of supply¹¹. These include:

- *Comprehensive market analysis* – an analysis of the needs of all older people and whether supply is meeting those needs (in volume, type, quality and price) is a vital first step. Data is routinely collected about council supported care users, but not about self-funders. This needs to be addressed, in order to calculate the level of unmet need or care shortfalls.
- *Commissioning* – outcome based commissioning, and commissioning beyond care for the whole population, will help to ensure the wider needs and wellbeing of older people are met
- *Purchasing* – local authorities must consider how their purchasing strategies for state funded older people affect providers and self-funders. This includes balancing spot and block contracting, for example
- *Sharing information with providers* – providers need to be included in the commissioning process, and the comprehensive market analysis should be shared with them to enable them to spot emerging trends and niches in the market
- *Providing services in-house* – this is an important mechanism by which supply can be increased and market failure can be addressed
- *Shaping on a larger scale* – regional or cross-local authority market shaping may be necessary to reflect the real 'places' in which people live
- *Overcoming barriers to market entry and growth* – this covers a variety of activities, including encouraging recruitment and retention, providing business support, overcoming planning barriers and tapping into national pilots and funding schemes

¹¹ Resolution Foundation, *Local Market Shaping* discussion paper (December 2008)

- *Improving the health of demand* – supply can be stimulated through stimulating demand. This in turn is achieved by creating better informed and more confident ‘care consumers’.

45. Market shaping should be focused on building healthy demand, healthy supply and stronger feedback loops between the two. It should also find ways of encouraging innovation in response to this feedback¹². In our view, the priority in coming months must be on *practical* work to build local authority capacity to act as market shapers. Further work is needed to develop metrics for success. We believe these metrics should rest on whether or not healthy demand and supply are established in local social care markets.

46. Healthy demand would involve:

- Clarity about what people are entitled to in old age, and what they will be expected to pay for themselves
- A well-developed system of information, advice, brokerage and advocacy
- Local infrastructure which helps people to access care (e.g. transport, housing)
- A range of products to suit different needs and levels of income and assets

47. Healthy supply would require:

- Effective mechanisms that enable providers to identify and respond to unmet and emerging demand
- Clear communication channels between providers, users and commissioners to facilitate feedback about quality and price
- Low barriers to entry to the market and appropriate freedom for providers to respond to new or changing demand
- Rewards and incentives for providers to be responsive to older people’s needs, delivering value for money and quality

Care navigation service¹³

48. Older people, their families and carers find navigating the system very difficult. In part this is due to the sheer complexity of the system. There is little awareness of what sources of information are available, and many existing sources are fragmented and overstretched. Historically, the majority of local councils do not believe they have a role in providing information and advice to self-funders and others whose income or assets put them beyond eligibility for state-provided care.¹⁴ All of this is compounded by the fact that often people do not plan for their care, so only start to find out about their options at the point of crisis – for example when they are under pressure to vacate a hospital bed.

49. The net result of this is that many people do not know where to turn for help, and risk making poor choices. Equally providers can lose out – poorly informed users may not be aware of their existence, and they may not buy as much or as often as they would if they had more information on their options. We therefore

¹² Resolution Foundation, *Innovation and Efficiency in Long Term Care* discussion paper (December 2008)

¹³ For more in depth analysis please see *Navigating the Way*, *ibid*

¹⁴ Henwood M and Hudson B., *Lost to the System? The impact of Fair Access to Care* (CSCI, 2008)

welcome the Green Paper's commitment to a national information and advice service as we believe it will address low earners' strong concerns about the complexity of the system, and their low awareness of where to go for help and advice.

50. We believe that the provision of advice and guidance about care services should form part of any universal entitlement for older people, supporting people at every stage, building upon but most importantly coordinating and extending the reach of the existing advice sector.

51. Our qualitative work and polling with low earners highlighted the following issues in relation to access to information:

- Lack of integration between social care and health services
- Lack of clarity about who to approach for information and advice. Most frequently cited places included: GP, Age Concern, family and friends and the internet
- Current system requires people to know what question they want to ask and responds better to crisis. For example self-funding low earners are not pro-actively offered support before their money runs out about their options
- Form-filling is complicated and confusing – low earners perceive a high risk that they will not access services they are entitled to because they have not filled in the form correctly

“Because my other sister done care work when she lived in London and so we sort of knew a bit about the care scheme anyway”

“I just sort of do it through friends, you know I ask questions you know what I mean”

“I asked friends who had had elderly parents what they had done”

“I phoned up maybe six weeks ago and they said they’ll have to send me another form to fill in [...] so it took them about four or five weeks to send the form, and then, it was a 16 page form to fill in. And I have filled it in and sent it back but all I want are a couple of rails, I’m not asking for anything else.”

52. Central to meeting people's needs is a service which integrates a range of support (information, advice, advocacy) on a range of issues (health, care, housing, finance and entitlements) to help people navigate the care system. This should form the 'first stop shop': a single, integrated source of information and advice, as the Green Paper proposes.

53. An important point from our research needs to inform the development of a national information and advice service. Older people do not distinguish between information, advice and advocacy, and so these three types of support will need to be brought together, enabling older people to use them seamlessly under a more accessible and intuitive concept of 'help'.

54. This help needs to be understood in the context of a person's care journey. Often low earners get lost in the system, too rich to qualify for state-funded support, but

finding the burden of their care costs extremely high. Their need for advice is not only at the first point at which they need some kind of care, but also further down the line, for example when their needs change, or when their assets are dwindling thus making them potentially eligible for state support.

55. A great deal of further work is required to map the care journeys of self-funders, whose routes in and around the care system are often more complex and opaque than those people whose care is provided and paid for by the state. It is only by taking this approach to the design of a unified information, advice and advocacy service that it can be targeted in the best possible way at those people who need it most.

56. There is already much capacity in the system that could be developed. Fragmentation will need to be minimised in the information and advice sector. We also believe that more work will be needed to build capacity around advocacy and brokerage services, the bulk of which is currently delivered by small third sector organisations. We believe such a service should be delivered via the appropriate range and mix of channels. Ultimately it should be a national system, but combined with a network of local 'first stop shops' commissioned by the local authority.

57. Finally, we agree with the Green Paper's view that a trusted brand will need to be developed to encourage take-up of advice and information. Government should draw on strategic and social marketing techniques to reach out to all older people and their carers who stand to benefit from these services.

SECTION 3: FUNDING

Question 3: The Government is suggesting three ways in which the National Care Service could be funded in the future:

- **Partnership – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.**
- **Insurance – As well as providing a quarter to a third of the cost of people’s care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.**
- **Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.**

Which of these options do you prefer, and why?

Should local government say how much money people get depending on the situation in their area, or should national government decide?

59. The Green Paper focused on funding options for the future system of social care. It is clear from projections of demographic change that significantly more money will be required, simply to stand still. Already resources are extremely constrained with growing numbers of local authorities tightening their eligibility criteria and restricting funding to those with ‘substantial’ needs.¹⁵ We agree that a new funding settlement remains critical in the light of demographic change which will increase demand for long-term care over the next few decades, with an increasing number of people living longer but with more complex conditions such as dementia.

60. These future needs are in the context of a system where individuals are already contributing significant amounts to the funding of care, either because they do not qualify for state support, or because they want to raise the quality of the care they are using. One recent study estimated that 30 per cent (£3.52 billion) of the total annual spend is purely covered by private funders. Once council charges and top-up fees are included, this private expenditure increases to approximately £5.9 billion, or 50 per cent of the annual spend on social care. Private expenditure represents nearer to three-fifths of the money spent on the care homes sector.¹⁶ All of these estimates exclude the significant contribution of resources in the form of informal, unpaid care.

61. This current system has a number of problems. It is inefficient – for example:

- It incentivises more costly remedial care, which is less complex to organise and to fund than a package of home-based support

¹⁵ In 2005/6 this figure stood at 54 per cent of councils; by 2007/8 this had risen to 73 per cent

¹⁶ Forder, J., *Self-funded social care for older people: an analysis of eligibility, variations and future projections*, October 2007 (CSCI)

- It leads to the premature use of residential care as people are unable to access their assets while remaining in their homes
- A lack of joined up working across social care, health and housing creates inefficiencies and duplication
- It is likely that the prevalence of informal care masks further inefficiencies and a level of unmet need (the Social Market Foundation estimates that 6000 higher-need older people and 275,000 lower-need older people are not having their care and support needs fully met¹⁷)
- The market for products to enable people to make private contributions to the costs of their care is relatively undeveloped and people are often unaware of, or do not trust, the products that are available.

62. It is also unfair – for example:

- One of the reasons that older people enter residential care early is because they are too rich to qualify for state-supported domiciliary care but unable to access their assets which are tied up in their home
- It creates a two-tier pricing system which penalises self-funders, who lack the purchasing power of local councils block-purchasing provision
- The means test penalises those with modest assets and low incomes and creates a ‘cliff edge’
- This ‘cliff edge’ is not uniform – variations in eligibility criteria across (and sometimes within) local authorities make it hard for people to know what they are entitled to, and what they need to plan and save for

63. It is clear that additional collective resources will need to be found to simply carry on delivering the current level of provision for care and support. As the Green Paper acknowledges, moving towards a National Care Service implies that additional collective funds will need to be found, through some combination of:

- Investing in prevention early, rather than spending on remedial action when crisis hits
- Supporting innovations that help to keep people active, healthy and in their own homes, such as the development of Telehealth
- Making efficiency gains through the better integration of care, health and housing
- Redirecting funds from other public services
- Reforms to the tax and national insurance system in the light of demographic change

64. But the scale of demographic change, coupled with a shift away from seeing social care as a safety net to seeing it as a universal entitlement, means that collective resources will be necessary but not sufficient to meet demand. In response to this, the Green Paper consulted about three broad options for funding future social care equitably and sustainably, having discounted a ‘do nothing’ and a taxation-based option:

- *Partnership* – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.

¹⁷ James Lloyd presentation, November 10th 2009

- *Insurance* – As well as providing a quarter to a third of the cost of people’s care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- *Comprehensive* – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

65. Our view is that further work is needed to clarify the terms of the ‘universal entitlement’ before a lasting funding settlement can be agreed. From the perspective of low earners, further detail is needed on the funding options before they can be assessed against fairness and affordability criteria. It is also unlikely that any single funding model proposed in the Green Paper will provide the full solution to increased demand for social care. Our work at the Resolution Foundation has highlighted some important principles that must be taken into account before entering a detailed debate about the best model of funding.

66. First, we believe there is a strong case for a *mixed market* solution of both state-sponsored and private funding mechanisms that co-exist and complement each other, and enable individuals to plan for old age through insurance and savings, as well as equity release products designed to help asset-rich, income poor care users. This diversity is necessary to meet individuals’ needs, resources, attitudes to risk and inclinations to plan, and a mixed market approach is likely to be the only solution that delivers sufficient funding into the system in the light of growing demand.

67. Second, we urge government to explore a *staged approach* to sustainable funding, where new options and approaches are introduced over time to meet the needs of different generations. For example, today’s older low earners are asset-rich and income poor. A solution which works for them may not be as relevant or effective for younger generations, who are less likely to have housing wealth, and who have more time to save and plan for their old age. A forthcoming paper from the Resolution Foundation highlights changes in home ownership trends and argues that there is a 30 year window of opportunity during which housing wealth can play a critical role in paying for social care. However for the children of the baby-boomer generation, focusing on savings and insurance options as well as tax reforms, will be more important¹⁸.

68. Third, a new funding model remains critical in the light of demographic change, but this model must relate more explicitly to a reformed delivery model that is more efficient, fair and personalised. Enabling the market for social care to work effectively is vital to improving outcomes for older people, and for delivering a vision of greater choice and personalisation.

69. While we do not feel the Green Paper provided sufficient analysis of costs and models to reach a firm conclusion on the best way forward, our work with low earners suggests that in the *short-term* a mixed funding model that combines elements of state-supported (though not necessarily delivered) care insurance

¹⁸ Williams, P., *Home Equity: accumulation and decumulation through the life cycle* (Resolution Foundation, forthcoming)

and equity release products with a reformed system will best meet the needs of low earners.

70. However we believe that longer-term, much greater consideration must be given to how people can pay for their care during their working lives through a tax-based system or a pre-funded insurance-based model. We believe that for such systems to work for low earners, there will need to be strong incentives in place, and some degree of compulsion to encourage participation. Other research we have done shows that low earners are less likely to participate in voluntary savings and insurance schemes.

“It’s got to be started a lot earlier, it can’t be started at retirement age.”

“You can’t really start paying at 65 can you? ‘Cos what you going to pay with, when you’re not working?”

71. Our response offers some reflections on how additional resources can be unlocked via direct individual contributions, based on the previous research and analysis of the Foundation.

Affordability of paying for care

72. Before focusing on this question of unlocking more money to fund social care, it is important to reiterate that low earners are squeezed by the current eligibility criteria, and the Green Paper gives little indication of whether or how this will be addressed. Despite their low incomes, over three quarters of low earners are likely to be deemed ineligible for state support (usually thanks to their housing assets), and we believe that the current limits on eligibility – particularly the capital limit of £23,000 – are set very low. Part of the debate following the Green Paper must be about whether as a society we wish to extend these limits, particularly given some evidence that unmet need, measured in hours per week, peaks for quintiles 3 and 4¹⁹.

“How can you pay 400 quid a week on £21,000? It’s a scandal isn’t it? An absolute scandal”

“I’ve never asked the state for anything until now, and I don’t want charity now, I’d like a little help, but I think what they are charging me now, it’s not realistic and it’s unfair.”

73. Regardless of the outcome of the debate about raising the capital threshold, three issues relating to care costs and affordability need further consideration if low earners are not to lose out in reforms to the funding and delivery of social care in the coming months and years.

74. First, it is not clear which costs are covered any of the future funding models proposed in the Green Paper. For example, a year in residential care is likely to cost approximately £26,000. Care provision is about £12,000 of this cost; the

¹⁹ See presentation by Jose-Luis Fernandez at King’s Fund, August 2009

remainder is hotel costs,²⁰ which are not covered by the funding options presented in the Green Paper. Similarly in domiciliary care, it is not clear whether 'everyday' support – for example shopping and companionship – are included as part of any future funding settlement.

75. Gordon Brown's recent promise to provide free personal care for those with the 'highest' needs confuses matters further, creating a cliff edge between those who qualify, and those who are just below, as well as leaving those people with mid-level but long-term personal care needs to accumulate 'catastrophic costs'. Similarly the recent Conservative proposal to create a compulsory insurance model only covers residential care rather than domiciliary care and does not explain how low earners and others lacking the £8,000 required could pay the premium.
76. In short, while this lack of clarity and transparency continues it is hard to see how the system becomes any fairer or simpler for low earners to navigate and plan around.
77. Second, further work will be needed to speed up financial eligibility assessments. A recent CSCI study found some cases where the outcome of a financial assessment took between three and five months to come through. Given low earners tend to have few savings these months leave people vulnerable to arrears building up and a crisis being triggered.
78. Finally any future system of social care needs to consider how to help people to plan ahead. Many people who start to use care as self-funders ultimately qualify for state support as their resources are depleted over the years.

"I can cope with what I've got, but frankly couldn't afford any more [...] I've got to look at a year or so ahead though, am I going to be able to do for myself what I can do now, I don't know [...] The way I'm being charged, ideally I would like to put a little away each month and say right, now that is if I need to have more care in a year or so's time... but at the moment I'm just about coping every month."

79. For example Buckinghamshire County Council conducted a study that showed that 12 per cent of people whose care was paid for by the council were ex self-funders; however they were disproportionately expensive, as the care choices they made as self-funders were more costly than what was offered by the council.²¹ Improving monitoring systems and providing greater support for financial planning is an important part of managing the costs of care to low earners.

"What the government does is make us poor before they help"

80. It is worth noting that it is this final point that leads to many low earners feeling that the system is unfair.

²⁰ Jose Luis ppt at Kings Fund event

²¹ quoted in Henwood, M and Hudson, B., *A Parallel Universe? People who fund their own care and support – a review of the literature* (November 2009)

“It’s like people have worked all their life to pay for their home, their bit of savings, whatever they’re going to do with their savings, and then it all goes into, unfortunately they become ill, and then it all goes into their care needs which is quite sad really.”

Enhancing individual contributions to the future funding of social care

81. The economic downturn and anticipated fiscal contraction, coupled with demographic change and a decline in the working-age population, all point to the fact that existing collective funds for social care are likely to be in short supply. Already local councils are tightening eligibility criteria for state-sponsored provision, with 73 per cent of local authorities restricting funding to those with ‘substantial’ needs. Therefore it seems inevitable that one way or another direct funding by individuals will need to increase. This is all the more so the case if government is committed to expanding what counts as ‘care’ through the development of a National Care Service.
82. To facilitate this, work needs to begin now on developed a range of markets that will help people plan and pay for long-term care. Differing care needs, resources, attitudes to risk and inclinations to plan meant that a single funding mechanism is likely to prove inadequate. In our work on funding options at the end of 2008 we identified three potentially mixed markets that could facilitate an increase in direct and indirect funding by individuals²².

Equity release

83. First, we considered equity release products. These could be particularly relevant for the current older generation. However there are a number of issues for low earners with the market for equity release products as it stands:
- Access is restricted for owners of lower value properties
 - The relatively large initial minimum drawdown risks benefit recipients losing their entitlements
 - The product remains unpopular with low earners – they do not trust it following the negative press around ‘sale and rent back’ schemes. It is seen as ‘unfair’ to not be able to pass on a house to future generations
 - Independent Financial Advisers and brokers are reluctant to sell the products due to their complexity. Regulations introduced over the last decade now require brokers to obtain a special licence to sell equity release products
84. These issues are not insurmountable. State support for equity release could help the private market to develop, as well as improving trust in the product. Government could encourage the development of equity release products – and potentially supply them directly – for those who only need relatively small amounts of equity to pay for domiciliary care or preventative measures such as home modifications.
85. We recently held a workshop to discuss these issues with local councils. The findings of our more recent work on how to improve and scale up existing equity

²² Resolution Foundation, *Facilitating Increases in Long Term Care Funding* discussion paper December 2008

release and deferred payments schemes is forthcoming, and will be available from our website, www.resolutionfoundation.org.

Long-term care insurance

86. Second, we considered pre-funded (as opposed to immediate need) long-term care insurance. As the Green Paper argued, such insurance schemes pool risk across society and therefore have associated welfare benefits. However, as with equity release schemes, there are currently market failures in existing insurance models that need addressing. For example providers face difficult pricing decisions because of the uncertainty associated with longevity estimates, resulting in premiums that err on the side of caution. Conversely individuals tend to underestimate the risk that they will need to fund care, meaning that they perceive the premiums to be poor value for money, resulting in low take-up.

“You never seem to qualify for the one thing you need and the premiums are horrendous, and it would probably be the same for long term care”

87. The result of this is that there are just 40,000 ‘pre-funded’ products sold each year – a tiny number given the 9 million people aged 65 or over who are not entitled to state support when it comes to care. Similarly, the ‘immediate needs’ annuities – which only pool risk among those already needing care – are only bought currently by very wealthy households.

“If we’re all going to pay in, say from age 25 for example, I think you’ll find a lot of people would want to have guarantees that it’s not going to be the same as collapsing pension fund and whatever, and that the government aren’t going to misappropriate those funds and gear them elsewhere and will it still cover my residential care and whatever”

88. For low earners specifically two further issues arise. First, current long-term care insurance products are out of reach simply because the premiums are too expensive to pay for. And second, our analysis indicates that low earners are generally less likely than higher earners to take up insurance products. For example only 39 per cent of low earners have a life insurance policy, compared with 58 per cent of higher earners – a pattern that is mirrored in ownership of payment protection, contents insurance, income protection and critical illness products. This may point towards the importance of incentives and soft compulsion (similar to the auto-enrolment model being introduced for pensions) to encourage take-up.

“You will always get those that hedge their bets and then rely on others, so I would make it compulsory.”

89. The Green Paper posed the question of whether any future insurance scheme should be delivered by government or the private sector. Our view is that a state-sponsored model will generate higher levels of trust and increase the range of options for developing products that meet the needs of low earners. For example, equity release models could be used to enable asset-rich, income-poor low earners to pay the premiums of an insurance scheme. The National Care Fund

proposed by the International Longevity Centre is an interesting model which is based upon ability to pay rather than on risk alone, and offers flexible payment options including the use of equity release.

90. There is no reason that the functions of an insurance scheme could not be delivered via the private sector. However, the government would need to take action to tackle the issue of low trust in this solution. It would also need to play a role in terms of ensuring that people had access to appropriate and affordable financial advice, and if the insurance scheme was compulsory, there are obvious regulatory implications for the state.

Long-term savings products

91. Finally we considered a third market – that for long-term savings products. Among the post-baby boomer generation it is not clear what asset holding will look like in coming decades. It is quite possible that higher levels of personal debt among younger cohorts coupled with delayed access to the housing market will have a significant impact on the housing wealth enjoyed by future generations. Therefore identifying and supporting alternative asset-building vehicles is an essential part of helping people to plan for their old age.

“They should have something like the Child Trust Fund, encouraging people to save for their old age. But I think people have been put off by the trouble with the pension funds. Saving for long term care could turn out the same way.”

92. While awareness of privately-provided products such as ISAs and pensions is widespread, it remains the case that many people enter retirement with inadequate savings. The government is already moving to tackle this issue through improving personal pension provision, including the introduction of auto-enrolment and personal accounts. Specific and progressive tax incentives at the point of saving coupled with soft compulsion could help to encourage further saving for old age among younger cohorts.

Stimulating demand as well as supply

93. Concerted industry and state action could provide a comprehensive range of product options that co-exist and enable individuals with different care needs, resources, attitudes to risk and inclinations to plan to approach long-term care in a way that best suits them. However, our work with low earners suggests that the barriers to take-up of long-term care financing products are also rooted in demand-side market failures.

“[My dad] had always been fit and healthy up to that time he had the heart attack [...] I don't think enough people do think about, you know, the future [...] That would have been a good think to think about doing for my dad, or my dad doing, years ago”

94. Individuals' ignorance or unwillingness to consider the need for long-term care financial planning will need correcting if products are to be taken up: improved demand would be likely to stimulate supply better than improved supply would

encourage demand. Qualitative work and polling which we have carried out with low earners indicates low levels of awareness about the need to plan and pay for care. People were sceptical about the value for money of privately-delivered schemes and were much more amenable to state-run equity release and insurance schemes, where there would not be a profit motive. It was also felt that a government scheme would be more trustworthy than a financial provider product.

95. These insights point to the importance of thinking about the future funding of social care as a *staged approach*, rather than a choice between different funding models, whereby mandatory schemes and working-age solutions to funding are introduced over time, as the public case is made and communicated about the importance of planning for old age. The state must take responsibility for ensuring that the reality of long-term care funding is communicated to the public with urgency and honesty.
96. Work can begin on this now, and we believe that action designed to improve supply of, and demand for, appropriate products should be taken regardless of the wider debate about funding and reform of social care. Working in tandem with financial service providers, who have an interest in increasing demands for their products, the state also has a duty to ensure that good quality, objective money guidance is provided that covers the full range of available products and allows individuals to select solutions most appropriate to their circumstances. Armed with this knowledge, individuals will then be better placed to take responsibility for their long-term care needs and plan appropriately.
97. The Green Paper is at risk of posing a false choice between funding options. Rather, the debate must focus on how to achieve a staged approach towards a sustainable system that engages working-age adults in planning, saving and insuring for their care through a variety of mechanisms. The policy intention must be to increase collective and individual contributions to the costs of care simultaneously. This will require a range of approaches.
98. In addition, the government will need to think about how best to combine and blend the different markets we have described here. For example, can we create a system whereby individuals can pay for insurance premiums using a deferred payment or equity release option? Could people use an insurance-based model to cover the costs of their residential care, while accessing an equity release scheme to pay for their hotel costs? This is the kind of level of detail that now needs to be addressed to move the debate forward.
99. The process of reforming social care still has a long way to go. We urge the government to work closely with stakeholders to clarify outstanding questions, and to design an approach that communicates the necessary ambition and urgency to all concerned.

ANNEX A: summary of in-depth interviews with self-funding low earners conducted in October 2009²³

Kathy, North London

Helped to organise care for her 85 year old father Dave, along with her four sisters

Profile of care receiver

- Dave, aged 85
- Started out as a radio engineer and also worked for a newspaper just before WWII
- He went into the Army to fight in WWII
- He started as a car salesman in his late 20s and that's what he worked as for the rest of his career (worked for companies but also worked for himself on many occasions). Even did a few deals recently.
- Dave got married in his late 20s and has five daughters aged 62, 54, 52 and two twins aged 50. He did have a son but he died of complications with Hepatitis C and liver disease when he was in his 50's.
- He left home around 1973 and was absent from his family for about 6 years
- His first wife passed away 30 years ago but they were already separated and he was already with his second partner who he married after the death of his first wife.
- He married again after divorcing his second wife and this was when he came back to his family
- When his third marriage ended he went back to his second wife who he stayed with for 33 years
- Dave stopped working full-time in his 70's although Kathy said he never really stopped working- still gets on the telephone and does deals, etc.
- He had a heart attack nine years ago in 2000
- He was diagnosed with lung cancer in March 2009
- He started receiving care at home in April 2009
- Dave's second wife had a brain tumour and passed away in June 2009
- He has lived all over Greater London, now lives outside of London and has been in his current house for 16 years which he owns
- Dave's eldest and middle daughters live near him

Care Journey

- Dave had a heart attack about 9 years ago.

²³ All names have been changed to protect the identity of the respondents

- He got back together with his second wife and she did everything around the house for him, really took care of him.
- He was diagnosed with lung cancer in March 2009.
- Unexpectedly, Dave's second wife was diagnosed with a brain tumour around May 2009 and died shortly after.
- Kathy said that if Dave's second wife was still alive they probably wouldn't have needed to hire a carer or if they did, it wouldn't be for as much time as they have now.
- She was saying the carer really does the stuff that they can't do because they're his daughters – personal care, etc.
- She said he'd never considered previously that he might need some form of care: ***"I think he thought he was going to be looked after for the rest of his life by women!"***

Typical Week

- Dave receives 30 hours of care each week
- The carer (from an agency) comes round three or four times a day – makes all three meals and provides personal care as well– baths, etc. Sometimes looks in on an evening to make sure he's okay.
- He goes to bed around 10pm.
- Kathy and her sisters do all of the other work – change beds, ironing, hovering, etc.: ***"When I go there I always stay down there with him and then my other sister she went there on Saturday for the day with her husband. So he's quite fortunate that we're always sort of, we sort of do a little rota, like my sisters taken him to hospital today and then my other sister she goes up changing his bed and takes his washing in and his ironing, she has an ironing lady, and then when I go there I do it. So we sort of got, also, with the care we've also got a little rota going."***
- Dave's neighbour below looks in on him and actually heard him once when he fell.
- He now wears a lifeline alert around his neck.
- Kathy is happy with the care he receives but pointed out that she and her sisters do a lot of what a carer would need to do so they are very lucky they can do that for him.
- Dave is very sociable so an important aspect of the care his daughters provide for him is company

Funding

- A friend of one of Dave's daughters used to work as a carer so she was able to advise them on what they needed to do once they realised Dave needed care: ***"One of my sisters friends used to work as a carer down [where he***

lives], so she knew who to, sort of, anyway it was done through social services...”; “Because my other elder sister done care work when she lived in London and then my sisters friend so we sort of knew a bit about the care scheme anyway...we knew that you don’t get it for nothing if you’ve got a little bit of money or property.”

- They got social services in to do an assessment and were very pleased with the level of service they received. Kathy said they came in right away and were very quick and efficient.
- She said for the first few weeks her dad didn’t have to pay but after that time he had to start paying for the care he was receiving.
- MacMillan Cancer Support also worked quite closely with social services to provide a joined-up service for Dave.
- From the assessment they were able to get rails fitted in the house for Dave so he could get around a bit easier. They also got him a more suitable Zimmer frame as his previous one was too big.
- Independence is very important for Dave so they knew it was important that he stay in his house as long as he can. She said he would hate being in a care home.
- He didn’t qualify for funding support as he owns his own home and has savings.
- One of his other daughters handles his bank accounts and his finances in general.
- He currently lives off his savings and the money that his wife left him and this is how he pays for his care.
- He also receives incapacity benefit as he has cancer.
- Kathy feels it’s unfair that her father worked hard and saved all of his life and now all of his money is going on paying for care, etc.: ***“I do feel like my dad worked all his life and I think when people get to a certain age or they have a serious disability or they need care I think it should be funded...And then people that have actually, maybe not even worked, or worked or whatever, if they haven’t got anything, or they haven’t got any money or they haven’t got any property, then it’s all funded isn’t it? It’s like people have worked all their life to pay for their home, their bit of savings, whatever they’re going to do with their savings, and then it all goes into, unfortunately they become ill, and then it all goes into their care needs which is quite sad, really.”***
- It sounds like his daughters also help pay for various things. For example, Kathy said that one of her sisters has always paid for his golf club membership which costs around £800 - £1000 a year. This was the first year she didn’t pay it as their father is now too unwell to pay golf. She mentioned that a couple of her sisters have quite a bit of money.

- Kathy liked the Insurance Model as she said it's important for people to plan for their care: ***“He’d [her dad] always been fit and healthy up until that time when he had the heart attack, I can’t remember my dad ever being ill.”; “I don’t think enough people do think about, you know, the future” “That would have been a good thing to think about doing for my dad, or my dad doing, years ago”***
- Dave had always been taken care of by the women in his life and had assumed that if he needed taking care of in the future, he’d have his wife to do that. So when his wife passed away and they had to organise care for him, it was unexpected.
- Kathy said it’s made her think about the potential need to plan for her own care in the future as before her father got ill she’d never considered it before.

Beth, North London

Helped to organise care for her 97 year old mother Dorothy, along with her sister and brother

Profile of care receiver

- Dorothy, aged 97
- She was born in 1912, the daughter of Romanian immigrants
- She was one of seven children
- 'Born and bred' in East London. Her father had a store there and they all lived over the store in a couple of bedrooms
- Left school at 16 and worked as a milliner (hat maker)
- She was also very musical when she was young and the school wanted her to go on and do a music degree but she couldn't, she had to go out and work
- Got married at 24 (husband from a similar background) and had two girls and a boy
- Her husband bought a shop and sold TV's and radios. He worked very hard, she worked with him and they lived over the shop
- When he went to fight in the war in the Royal Air Force, she would open up the shop for him and take care of business
- They moved to North West London after the war
- Her husband retired at age 65 and passed away in 1983, aged 69. She has been a widow for 26 years
- When her husband passed away she moved from Ealing to Finchley so she could be nearer her grown up children and owns her own flat
- She sang in a choir into her mid-80s
- She didn't need any care until she was around 92 when her family realised she needed help
- She is now 97 years old

Care Journey

- Dorothy had been living at home by herself up until one day she used a knife to get toast out of the toaster and ended up electrocuting herself (flew across the room from the impact). This was when her family realised she needed to have some care at home.
- Interestingly, it's not that this one incident prompted her move into care, more so it made them realise that the need for care was already there and they needed to do something about it.
- At this point Dorothy's family 'asked around' to find out what support was available: ***"I just sort of do it through friends; you know I ask questions you know what I mean"***. They only asked friends and never contacted social

services as Beth felt they wouldn't get any help or support. Beth said she knows her mother wouldn't qualify for support as she has too much money (owns her own home and has savings). Interestingly, she didn't know what the threshold for support was (this came up when we talked about the funding system): ***"We asked around really, because I knew she wouldn't get assistance from social services really, because she wasn't in that category. She had savings, my father had left her pretty comfortably, she was never a big spender. I asked friends who had had elderly parents what they had done, and my sister in law, her mother had died recently, she'd had Alzheimer's, and they'd had various carers coming in and she knew somebody so we interviewed this young person"***

- Beth said she requested some grab rails for her mother's house from social services. Apparently it took five weeks for them to acknowledge her request and another six weeks to send her the form. Once it had arrived the form was 16 pages long. Beth said having to provide so much information made her feel like her mother wasn't entitled to the grab rails which is unfair. She knows she entitled to them so why do they make it so hard? She said if this is how hard it is to get grab rails, she knows trying to get funding support for Dorothy would be an even bigger waste of time. ***"I phoned up maybe six weeks ago and they said they'll have to send me another form to fill in as I hadn't been in touch with them for about a year. So it took them about four or five weeks to send the form, and then, it was a 16 page form to fill in. And I have filled it in and sent it back but all I want are a couple of rails, I'm not asking for anything else."***
- Beth also said at one point a few years ago they went to get her mothers' hearing assessed. Initially they went through the NHS but the queues were so long and the quality of the hearing aids so inferior they decided to go private. It means they have to pay for it but it's worth it for shorter waiting periods and better quality hearing aids.

Typical Week

- Dorothy has a carer who stays with her from 5pm until 10am every day. They prepare all of her meals and generally keep her company.
- This level of care was enough initially, but she now also has someone come in for five hours during the day to warm up her lunch, spend time with her and generally keep an eye on her. This carer also does hovering and cleaning.
- At least one of her children stops by every day, they all live in the area.
- On weekends Dorothy goes to one of her grown up children's houses during the day.
- She likes to read the newspaper although she finds it hard to watch the news on TV anymore.

- She also likes to crochet and Beth said everyone in the family has a crocheted scarf from her.
- Her children do all of her shopping for her and they pay for it with her money. Beth said the carer will phone up to say what they need from the shop and Beth or her brother or sister will go to the shop and buy it. They also buy clothes for Dorothy (also using her money).
- Beth said her mother is increasingly only comfortable in her own home.

Funding

- Dorothy's income in retirement comes from her state pension and her savings - apparently her husband left her a lot of money. She also receives some kind of allowance but Beth couldn't remember what kind (attendance allowance?).
- She owns her own flat which she lives in.
- Beth said her mother initially minded spending money but doesn't anymore. Her children arrange all of her care and Dorothy doesn't actually know anything about how much it costs.
- Beth handles all of her mothers' finances. She said it worked out this way because she's retired so has the time and is also more organised than her brother or sister. She said she phones up her sisters' financial advisor from time to time when she needs help on something specific.
- Dorothy was originally able to live off the interest from her savings but now she's living off the capital which Beth finds worrying.
- Beth said she knows that if she asked the state for support for her mother she wouldn't get anything because her mother has too much money.
- Beth said they might need to increase the amount of care that Dorothy receives at home at some point but it's preferable to keep her in her home as she likes her independence and wouldn't want to go into a care home.
- Beth said that, while her children and her nieces and nephews are all wonderful, she can't see them taking care of her or her brother and sister the way they're taking care of their mother. She feels this is a generational difference.

Funding Models

- Beth seemed to like the partnership model the best.
- Beth's belief is that one should always save if one can but that means into a general savings pot, not something specifically for long term care.
- She didn't see the point in saving for long term care and then potentially not needing the care and so wasting the money.
- She feels that people should pay at the point of entry into the care system.

- Beth didn't see the point in targeting such funding models at people under the age of 80. She said most people between the ages of 65 – 80 are perfectly fit and healthy and it's usually after the age of 80 that health problems happen.

Clare, Surrey

She and her husband Allen helped to organise care for Allen's 81 year old father

Profile of care receiver

- Derek, age 81
- He was born in 1928
- Lived in the South West his whole life up until 2006 when he moved to Surrey
- Was in the Army during WWII – lost his trigger finger
- Became a qualified carpenter and was superb at his work
- Got married in 1953 at the age of 25
- Had one son with his wife
- Worked for many years as a carpenter
- He got divorced in 1981 after 28 years of marriage
- He used to love rugby and used to both play and watch it
- Loves classical music and the opera
- Good health until 2000 when they noticed excessive weight loss and he was diagnosed with bladder and bowel cancer

Care Journey

- Derek was in good health up until 2000 when they noticed that he had lost a lot of weight and wasn't eating. He became very unwell, was diagnosed with bladder and bowel cancer and had surgery which he recovered well from.
- He came to live with Clare and Allen and stayed there for six months before going back to his self-contained flat in the South West.
- Derek and his ex-wife Laura (Allen's mum) seemed to be getting along very well at this point so Clare and Allen started to think that it might be an idea to take out a second mortgage on their house so they could buy a flat for Derek and Laura to live in nearby in Surrey (they were still divorced but could live together as companions).
- Derek sold his flat in the South West and gave all of the money to Clare and Derek to put towards the mortgage on the flat. His contribution was £69,000 and the flat cost around £250,000.
- Derek and Laura moved into the flat in Surrey in August 2006. Around nine months later, Laura came to Clare to say that Derek was not quite himself – he was moody and irritable. A few months after that she said she'd had to leave the flat as Derek had become aggressive. They took him to the doctors who thought he might have dementia. Eight months later Derek was getting violent and they got him properly assessed, at which point social services stepped in. They got social services to do an assessment in February 2007. Clare said while their service was great, they did treat Clare and Allen with a

lot of suspicion when they found out that Derek had sold his home and given the money to Allen to pay for the flat that was in Allen's name. Clare said they treated them like they had done it on purpose so that they could qualify for care support and she said they had quite a time convincing them that this wasn't the case. It didn't even make sense as Derek had not been unwell when he and Laura had originally moved into the flat in Surrey.

- At this stage social services weren't convinced that Derek needed to move into a care home just yet. Laura didn't feel comfortable living with Derek on her own, and as Clare and Allen had to travel a lot for work, social services said the best thing to do would be to put Derek into respite care. So he was in respite care on and off over the next year. Derek had savings but as his dementia had worsened, no one knew how much he had saved or how they could access it so Clare and Allen paid for the respite care themselves. This got quite expensive at times and Clare cited one incident where a 10 day stay in a respite care home cost them £1700. Later on, when they found out how much money Derek had saved and determined that it was less than £23,000, they got some money back but they did pay for the bulk of it: ***“Allen and I both travel because of our business and prior to Allen's father being put into a home they offered respite care. But because Allen's father had savings, we would have to use those savings or we would have to pay for the respite care. And for one business trip it was £1700 we had to pay to put him in respite care. And it actually made it not worth our while actually doing the business trip so we had serious issues regarding where were we to go”***
- They got Derek assessed again in March 2008 and health services determined that his health had gotten worse and so if he was in agreement, they would place him in a permanent, residential care home. By this point his funds had begun to diminish.
- Derek has been in the care home since June 2008. Clare said it's a very good care home but it's quite difficult as staff are under no obligation to provide certain services that you would get in a nursing home. For example, Derek has been struggling with his catheter, and in a nursing home one of the staff would help him but you don't get that kind of service in a nursing home. They're looking into seeing if they can get a nurse in two times a day to help Derek with this. Clare said they can't really think about moving him into a nursing home as that would cost an extra £400 a week, plus, for the sake of stability, it's best to keep him where he is at the minute.

Typical Week

- Derek is in a care home so care is provided 24/7.
- In the morning the carers come in with a cup of tea and ask Derek if he would like to get up

- He doesn't like to wash which apparently is common with a lot of Alzheimer's patients as they are often afraid of water. Washing is another service that isn't provided in the care home that they could get in a nursing home.
- The staff in the care home do all of Derek's' washing and ironing
- They also cook all of his food for him. Clare said the food there is very good and very healthy.
- They provide lots of social activities for the residents as well and take them on day trips.

Funding

- Derek now qualifies for state support as he sold his home in 2006 and gave the money to Allen and Clare for the flat that is in their name.
- Derek gets £151.86 per week from his pension and this goes straight to social services. He's supposed to get £20 a week for himself but Clare said this doesn't happen, it all goes towards his care. Social services pay the rest of his care costs which work out to about £400 per week. So the total cost of Derek's care per week is around £550. ***"They then did an evaluation of all his finances and at the moment now he has no pension, everything he gets, he's supposed to be left with £20, but he doesn't, they take it all, and social services now top up the rest. But he has a small amount of savings, but it comes underneath the bracket, so if he wants toothpaste or soaps or a new pair of socks or a shirt, we now pay for that"***.
- Derek received Disability Living Allowance in the past
- Derek's' ex-wife Laura still lives in the flat owned by Allen and Clare. She doesn't pay any rent but buys all of her food, clothes, bills, etc. She has savings of £32,000 and is worried about if she will one day need care as she doesn't want to give the government the money she saved for through her life: ***"She's already said, I don't know what to do, because I don't want to give the government the money that I have saved so hard for. I would prefer somebody to come in and give me help."***
- ***"At some point in the not too distant future we're going to have four dependent relatives. Where do you go? You need help. And my mum and dad are very fortunate in as much as, they have got some form of pension credit whereby they're given money and they can pay somebody to now do their laundry and their gardening. They've been given that because they're below the threshold on their savings. My father is also partially sighted and ideally things that my dad used to do that my mum now can't do they have to pay someone to come in, like maybe changing the plug and things like that, and for them it's upsetting. If that happens with Allen's mum she would phone us first and we would have to pay somebody to do it because she's basically***

going to be above the limit to get any form of pension credit or carers allowance or whatever. ”

- Clare and Allen feel there is confusion over who pays for what i.e. social services vs. health services: **“If the community nurse has to go in, then I presume it comes within the health budget rather than the council budge. I wouldn’t know because who employs the community health?...I haven’t got a clue I mean who employs a community health nurse? A health service? And the health service is funded by what, central government?”**

Funding Models

- Clare definitely did not like the Partnership Model. She didn’t think it was fair to expect people to cover such enormous costs when they’re in retirement: **“I think a lot of people would be up in arms with that to be very honest because they struggle to meet day to day bills and there are those that will say no we’ll opt out, I won’t take a chance, because they won’t have the money, they won’t be able to afford it”**
- She liked the idea of insurance but thinks that it should be compulsory so really was in favour of a model like the Comprehensive Model: **“You will always get those that will hedge their bets and then rely on others, so I would make it compulsory”**
- Clare feels that if you don’t make such a system compulsory, there will always be people who won’t opt in and who will then expect the state to step in when they need to cover the cost of care and everyone else will suffer: **“If I pay half, the government pays half, as long as I’ve got enough funds. If my funds then have gone, then the government take over that, and I would be more than happy to do that. But there will be those that don’t have any money at all, who decided to play the system, so therefore the government will have to pay for those and that’s got to be stopped”**
- The key part about Clare’s views on funding was that she thinks planning for care should take place much earlier than from retirement. She said her ideal model would be one where from the age of 25 people start paying into an insurance scheme, or a compulsory scheme so that by the time they reach retirement, they’re done paying and will get that care free if they need it: **“It’s got to be started a lot earlier, it can’t be started at retirement age”**
- She also said with any scheme where people are paying for insurance or are paying into a compulsive scheme, it’s absolutely essential that the government guarantees free care for everyone and that people get a choice on what care they get. She doesn’t necessarily feel like they have a choice now: **“But if he goes to a nursing home we don’t know where it would be. There’s one [nearby] but whether or not social services would pay for it, because as I understand it...I mean we can have a rough idea of where we’d want him to go, I personally don’t want him to move, I think it**

would really be a negative. But because we're not paying for all of it, he's only paying, well all of his pension goes to it, social services pay a far bigger chunk..."

- Clare said in their experience they kept hitting walls on what the government will pay for and what they won't and said that if she had been paying so much money into a scheme, she would expect all subsequent services to be free. She said this is especially important in light of what has happened to people's pensions, etc. in the credit crunch – people don't trust the government and the financial services as it is: **"If we're all going to pay in, say, from the age of 25 for an example, into this National Care, I think you'll find a lot of people in Britain would want to have guarantees that it's not going to be the same as collapsing pension fund and whatever, and that the government aren't going to misappropriate these funds and gear them elsewhere and will it still cover my residential care and whatever, and at the level they want, because some care homes, all standards are different...and I may pay in thousands of pounds and will meet part of that myself but I would want a choice in where I was going"**

Margaret, Surrey

Margaret receives care at home

Profile of care receiver

- Margaret, age 88
- She was born in 1921
- Got married in 1942 at the age of 21
- Her son was born in 1947
- Margaret's first husband killed in a road accident in 1950 when her son was 3 years old
- Government only gave her £1 a week for her child so she had to work
- She trained to be an accountant at night school
- She got a job and met her second husband at that company
- Margaret married her second husband in 1957 at the age of 36
- She started receiving care in 2004
- Her husband had to go into a care home in the last year of his life which cost them £884 per month
- Her second husband passed away in May 2009

Care Journey

- Margaret has had osteoarthritis for about 10 years
- It got very much worse 5 – 6 years ago and at that point her doctor said she needed help
- Her husband was at home at this point but he was diabetic so unable to help her with everything she needed
- Margaret's doctor got in touch with social services and then social services got in touch with Care Providers and she's been with them ever since
- She needs a frame to stand or get around
- She also has an ulcerated leg

Typical Week

- Margaret receives 17.5 hours of care a week from Care Providers
- A carer comes 1.5 hours in the morning
- A carer comes again at 6pm for half an hour – dishes up Margaret's dinner and pulls the curtains
- At 9.45pm the carer comes again for half an hour and helps her get ready for bed
- Margaret said the carers can be a bit erratic

- Her son does her shopping once a week, he'll often buy her prepared meals from Marks & Spencer which she likes
- She privately has a cleaner which she pays for herself, separate from the care service

Funding

- Margaret's husband developed dementia in the last year of his life so had to go into a care home which cost them £884 a month: ***"It nearly broke me. I was paying £884...I had to pay for that, that's where a lot of our savings have gone...it really knocked me"***
- Margaret owns her own home: ***"I'm beginning to think we were very foolish to have struggled and bought our own house...you don't get any help from anybody. And people who have wasted their money, they get everything given to them"***
- She has a small pension that her husband paid for from his employer
- Also receives her state pension which is £149 a week: ***"A state pension does not give you an exotic life"***
- Margaret pays £130 a week for her care and the council pays around £154 (17.5 hours of care x £16.25 per hour)
- She finds the amount that the council charges for care hard to justify: ***"I mean I have it out there in black and white, that the council charge, not just me but everybody using the services, £16.25 an hour...how can you justify that?"***
- The council funded most of Margaret's care when her husband was alive because everything was in his name. Now that her husband has passed away they're taking more money away. ***"It costs as much to run any house for one person as it does for two. The gas, the electric is the same, the water, I mean the household bills are the same for one as they are for two...It's very difficult, you know I've got to budget very very carefully now"; "As you get older, there are certain things you have to increase on, heating is one thing. Thousands of people like me have arthritis and you daren't be in a cold house"***
- Margaret has a large garden and she can't tend to it herself so she has to pay for a gardener to come every week. He'll also do odd jobs for her if she needs something doing
- She has to pay for a cleaner
- She has to pay for a hairdresser to come to her every week to wash her hair
- She has to pay for a chiropodist to come every five weeks which costs £38 a visit

- ***“When we have worked hard all our lives, and paid our taxes, I’ve never had a penny off of the Government, in medical costs or anything, and now when I need help they can’t take my money off me fast enough”***
- ***“We were brought up that you tried to provide for your old age, you did not depend on anything, and this is why you tried to buy your own home. But it now proves to be a very foolish thing to have done...I’d be better off if I’d whooped all my money up, you know, had far more holidays, and bought myself diamonds. I’ve never asked the state for anything until now, and I don’t want charity now, I’d like a little help, but I think what they are charging me now, it’s not realistic and it’s unfair”***
- Margaret finds it hard to cope financially: ***“They don’t ask, have you got problems, as I have. My expenditure is very heavy, not from choice, but because of my disability”***
- ***“I can cope with what I’ve got, and frankly couldn’t afford anymore...I would probably have an extra half an hour at the tea time call, more could be done to help me get ready, but you know I cope at the moment. I’ve got to look at a year or so ahead, am I going to be able to do for myself what I can do now, I don’t know. But I’ve got to think about it. But the way I’m being charged, ideally I would like to be able to put a little away each month and say right, now that is if I need to have more care in a year or so’s time...At the moment I’m just about coping every month”***

Funding Models

- Margaret thinks charging for care costs should be more reasonable
- ***“I think it’s somewhat unfair that we have to pay so much income tax on our state pension when we have a small private pension. I admit I resent it, because I paid for it and paid tax on it when I was contributing, now I’m getting it back I’m paying tax again. I think we are taxed far too heavily on our state pensions. If they would ease on that, we could help ourselves with our care. But if they’re not prepared to do that, I think the Government should subsidise, well let us say if they could reduce [the councils] £16.25 to let’s say, £10 an hour, I think they ought to subsidise the extra £6 if [the council] say they can’t cope without it, it should be shared between the two. I do not think that this heavy cost should be put on the shoulders, because in most instances it is with a retired person.”***
- ***“I think if you have paid tax all of your working life, I do feel it’s grossly unfair to have to pay tax on your pension that you have been paying for all the time, and paying tax...they ought to meet halfway”***

- ***“I think we should perhaps be asked to pay a reasonable cost, but not this exorbitant charge, I think the Government should pay a large portion of it...50/50 would be ideal”***
- ***“I’m prejudiced because I’ve looked after myself”***
- ***“You can’t really start paying at 65, can you? ‘Cos what you going to pay with, when you’re not working?”***
- ***“And quite frankly, I think it is almost unkind, that this awful worry of money is put on your shoulders at this age. You know, you shouldn’t have to sit at home every month when the money goes in the bank and you have to work out what have I got to pay this month, what bills are due, you know am I going to cope with it, or have I going to get a little bit out of what’s left of the savings?”***