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## **Response to the Department of Health Green Paper 'Independence, well-being and choice: Our vision for the future of social care for adults in England'**

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This response to the Green Paper [Independence, well-being and choice](#), draws on the significant body of research that the Joseph Rowntree Foundation has funded over recent years, concerning all the different groups of people who use social care services. In particular, the Foundation has been supporting a programme of research about the lives of older people since 2000. Developed by and with older people themselves, the programme examined the priorities that older people defined as important for 'living well in later life'. There were 27 projects funded within the programme. The Foundation has also funded key pieces of research concerning the implementation of direct payments, service user involvement, and generally on the experiences of people with mental health problems, people with physical and/or sensory impairments and people with learning disabilities.

We have responded to those questions identified in the Green Paper where our research and other programmes provide relevant findings.

### **Chapter 3, Consultation Questions 1 and 2: Vision and outcomes**

Paragraph 3.5 states: 'To experience a good quality of life everyone needs to have independence, the ability achieve their potential and the opportunity to participate fully in the life of their community. Of equal importance is the maintenance of positive relationships, respect and dignity.' Research funded by the Joseph Rowntree Foundation confirms that these are important aspirations, but – for older and disabled people – 'independence' does not necessarily mean doing things for oneself but having choice and control over any assistance needed.

**Recommendation:** The vision for adult social care should recognise that 'independence' means having choice and control over any assistance needed.

One very important aspect of people's lives is not mentioned in the outcomes –namely family and community roles and responsibilities. Most people who use social care services play an

important role in their families as parent, grandparent, partner, sibling, aunt/uncle, etc. Many also have important friendship and community networks and make a significant contribution to the local economy either through their roles as informal carers, or as sources for local employment. Social care services should seek to support and maintain such roles and relationships and recognise the role played by people to capacity building in their communities.

'Older people can play an active role as citizens. They often provide unacknowledged support to other older people or child care within families. In addition, they often have citizenship and community roles, for example, as local community representatives, organisers of community groups or participating in older people's forums' ([Older People's Steering Group, Foundations Ref. 044](#))

The recognition of family roles and responsibilities, and social care services' part in enabling people to fulfil them, is particularly important for parents who have mental health problems, physical and/or sensory impairments, or learning disabilities. The [Task Force on Supporting Disabled Adults in their Parenting Role](#) met over a period of two years and received evidence of considerable barriers experienced by disabled parents. There are particular problems with the relationship between children's and adults' services and with delivering disabled parents' entitlements to support under community care legislation and Fair Access to Care Services.

The Foundation also funded some work on disabled parents' relationships with their children's schools which found that [parents experience considerable difficulties in fulfilling their role](#) of supporting their children's education, difficulties which are compounded by social services and education authorities claiming that they have no responsibilities to assist.

**Recommendation:** Another outcome should be added – 'Fulfilling family and community roles and responsibilities'.

While the outcome 'Freedom from discrimination or harassment' refers to 'equality of access to services', the Green Paper does not address the fact that there are structural inequalities within the social care system. In particular, as the JRF [Task Group on Housing, Money and Care for Older People](#) pointed out: 'older people with significant health and care needs do not get treated on the same basis as younger people...Cost ceilings on care packages are lower than for younger people, so that older people only get safety net services at home and are forced into residential care earlier.

Forthcoming work from the Foundation on paying for long-term care urges: 'the most pressing need is to improve the fairness and consistency of the present system, especially the ways in which eligibility for home care is assessed and the distinctions between different categories

eligible for help with residential care'.<sup>1</sup>

**Recommendation:** The forthcoming White Paper should commit the government to removing discriminatory practices in the funding of social care services for older people.

The Foundation's Older People's programme found that ageism reaches into all aspects of older people's lives. Social care services could play a key role in challenging such ageism. This will require a fundamental shift in the way older people are perceived by social care workers: older people participating in the Foundation's programme reported that they find the two stereotypes – 'grumpy old men' and 'sprightly old ladies' – distinctly unhelpful. In order to bring about a cultural shift in attitudes within social care, older people must be fully involved in the design, delivery and monitoring of services.

**Recommendation:** Working with older people and their organisations, the Department of Health should promote initiatives to challenge ageism at all levels of social care services.

#### **Chapter 4, Consultation Question 4: Views on 'managing risk'**

Research funded by the Foundation highlights that professionals and people who need support often hold different views of both what is an acceptable 'risk' and what are the appropriate responses to 'risk'.

'Disabled people and carers had wider definitions of "risk" which practitioners appeared reluctant to recognise and respond to' (Davis et al., [Findings Ref. 318](#))

At the heart of such conflicts is usually a failure to listen to the individual's views and acknowledge their expertise. Recent research on the management of risk for mental health service users found that collaboration and information sharing between professionals and service users could often reduce disagreement and conflict.

'Many service users were aware that they could pose a risk to other people when experiencing psychosis and they wanted help to reduce the chances of this happening' (Langan and Lindow, [Findings Ref. 414](#))

Research on older men and women who experienced abuse found [a number of shortcomings in practices intended to protect vulnerable adults](#). These included inadequate communication between professionals and the vulnerable adult, a lack of information and advice, an unmet need to talk about experiences of abuse and a failure to holistically assess people's needs.

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**Recommendation:** The views of people who need support should be placed at the heart of policies and procedures for managing risk. The aim should be to work in partnership with people to enable them to take acceptable risks and avoid harm.

There is also a need to recognise that the physical environment in which someone lives can sometimes place them at risk and yet resources are not always available to provide necessary aids, adaptations or equipment. One research study, for example, found that [almost two-thirds of those who had had minor adaptations carried out felt less vulnerable to falls and accidents](#). Yet resources are not always available to take such accident prevention or, when they are, there are often unacceptable delays.

**Recommendation:** There is a need to recognise, within government Spending Reviews and local authority budget decisions, the role of aids, adaptations and equipment in preventing accidents, enabling people to live safely in their own homes, and reducing expenditure on health and social care.

### **Consultation Question 5: Views on self-assessment**

Much of the research funded by the Foundation on independent living has confirmed that disabled people are the experts on their needs. The Foundation's Older People Programme highlighted that many older people need 'that little bit of help' in order to maintain choice and control in their lives and prevent higher levels of need developing. There is much potential for self-assessment, particularly if assistance is to be made available at lower levels of need. Some people will, however, need advice, information and/or advocacy to assist with self-assessment and it will be important that such services are available.

### **Consultation Question 6: Do you have views on whether the SAP, the CPA and person-centred planning (PCP) should be further developed to provide a tool for use with all people with complex needs?**

PCP has been shown to be an effective tool to comprehensively assess people's needs, promote self-determination and lead to a more effective use of resources.

'Introducing a "person-centred" planning process led to people doing more things they really wanted to do, and realising more of their hopes, dreams and ambitions.' (Cole et al., [Findings Ref. 950](#))

PCP has led to people with learning disabilities being less reliant on statutory services, using 'mainstream' services more, developing more natural supports and generally being able to lead more 'ordinary lives'. PCP is very far removed from the 'tick-box' approach that sometimes unfortunately characterises the Single Assessment Process. The use of skilled

facilitators to place the individual's aspirations at the heart of the process has also been a key part of PCP, and in this way PCP differs from the Care Programme Approach, which is led by statutory agencies.

Evidence from the Foundation on implementing PCP says:

'Most of all, we need to implement person centred planning thoughtfully. Person centred planning is rooted in values and beliefs such as respect for persons, a passion for fairness, a trust in people's capacity to define and solve problems together, a recognition of the fallibility of systems, and a commitment to diversity and inclusion.'<sup>2</sup>

The research would seem to indicate that PCP is an appropriate tool to use in the development of individual budgets for people with more complex needs, as it has been shown to be effective in promoting self-determination for people with significant learning disabilities.

**Recommendation:** Well carried out Person Centred Planning should be used in the piloting of individual budgets to ensure that the new system includes people with complex needs.

### **Consultation Question 7: How can we encourage greater take-up of direct payments in under-represented groups such as older people and people with mental health problems?**

Direct payments are undoubtedly an important way of delivering the Green Paper's objectives.

JRF research found that [older people receiving direct payments reported feeling happier, more motivated and having an improved quality of life than before](#). There was a positive impact upon their social, emotional and physical health.

However, various pieces of research funded by the Foundation have also highlighted the barriers to increasing the take-up of direct payments. User-led support schemes were a driving force for the original implementation of direct payments and continue to be crucial to their extension. 'Champions' of direct payments within local authorities, and a culture within social services organisations which promotes self-determination, also continue to be key factors.

A study of the implementation of direct payments in the North East of England found that [direct payments worked best in local authorities where a supportive local authority](#)

infrastructure is combined with both an understanding of the principles of independent living and a commitment to partnership with users. Where direct payments are most successful, local authorities fund user-led support services as part of mainstream care provision.

There are very few direct payment support schemes providing peer support to people with learning disabilities and yet, according to research by Values into Action, availability of peer support is crucial to increasing the take-up of direct payments. Moreover, contracts tend to be awarded to those organisations which say they will work with the largest numbers of people for the least amount of money. The research concluded that:

'Flexible, person-centred creative ways of outreach, information provision and support achieve the best results in getting people with learning disabilities onto direct payments....Peer support does matter. It is about creating a local and national community of disabled people, including people with learning disabilities, who are experienced and expert in direct payments, who can inform and support others to access direct payments and, very importantly, who can inspire others to see that choice, control and opportunity in their own lives is possible.' (Bewley and McCulloch, [Findings Ref. D64](#)).

Research on direct payments for people with mental health problems concluded that advocacy services are vital to increasing the take-up of direct payments for this group and that outreach work and specific support services are needed in order to increase take-up among Black and minority ethnic service users.

A study of the implementation of direct payments for older people in three local authorities concluded that high quality support schemes were vital to increasing take-up of direct payments among older people. This research also echoed other research that local authority funding of support schemes does not always take account of the on-going support people need, particularly to deal with audit and administration requirements.

**Recommendation:** User-controlled, high quality support schemes, including peer support, should be an integral part of the government's policy of increasing the take-up of direct payments. Funding of support schemes should take into account the costs of the particular types of support required by different service user groups and contracts should not be awarded solely on the basis of the lowest unit cost.

Disabled parents have told us that direct payments are very helpful in enabling them to carry out their parenting tasks. However, the role of cash payments in supporting disabled parents is limited by the fact that Independent Living Fund grants cannot be used to pay for assistance with parenting tasks. Moreover, Disability Living Allowance does not reflect the

additional costs incurred by disabled parents. In our response to Improving Life Chances, we recommended that the government addresses these issues.

**Recommendation:** The Independent Living Fund's Trust Deed should be amended to enable ILF grants to be used for assistance with parenting tasks. Disability Living Allowance levels should take account of the additional costs of being both a disabled person and a parent.

## Consultation Question 10: Views on proposals to pilot individual budgets

Much research funded by Foundation highlights the issues that individual budgets are intended to address, in particular:

- The disempowering effects of the fragmentation of people's needs across different budgets and services
- The way in which self-directed support (for example, through direct payments) enhances the quality of people's lives and is an effective use of public resources.

The JRF Task Group on Housing, Money and Care for Older People, reporting in October 2004, pre-empted the Improving Life Chances report in suggesting the idea that direct payments should be extended to areas such as housing adaptations. The Foundation supports the idea of individual budgets and believes that, as envisaged by Improving Life Chances, resources other than social care should also be included.

**Recommendation:** A key aim of implementing individual budgets should be to prevent the current fragmentation of disabled and older people's needs across different budgets, programmes and organisations.

In terms of piloting the new system, it will be important that user-controlled organisations are at the centre of the pilots and that efforts are made to include those groups who have, so far, found it difficult to take up direct payments.

**Recommendation:** The pilot areas chosen for individual budgets should have strong user-led organisations, fully involved in the introduction of individual budgets. Pilots should cover all service user groups and resources should be put into enabling individual budgets to be used by those with more complex needs.

The Foundation has funded a significant programme of work on the experiences of disabled children, part of which has focused on transition to adulthood. [Young disabled people often face additional barriers in their transition to adulthood](#) created by a failure of different agencies

to work together, the fragmentation of their needs across different programmes and budgets, and little support for developing self-determination. [Such barriers are particularly acute for young disabled people](#) with complex health and support needs, many of whom have been placed out of the authority in residential placements. Improving Life Chances envisaged that piloting of individual budgets would also encompass transition to adulthood and the Foundation would support this.

**Recommendation:** Piloting of individual budgets should include at least one area focusing on young disabled people in transition to adulthood, and should pay particular attention to young people with complex health and support needs in residential placements.

Research on direct payments and people with mental health problems highlighted the artificial and sometimes unhelpful distinction between health and social care.

There is a need to review what direct payments cover in mental health: the distinction between health and social care in mental health is not an easy one, and arguably no longer relevant given the integration of health and social care to provide mental health services. JRF evidence shows that [the absence of a streamlined process integrated with the Care Programme Approach adds to the sense of direct payments being a burden rather than an opportunity](#).

The piloting of individual budgets provides an opportunity to address this artificial divide between health and social care and it will be particularly helpful if one of the pilot areas focused on how this could be done for people with mental health problems.

**Recommendation:** Piloting of individual budgets should address the integration of health and social care services for people with mental health problems.

The Foundation has funded research on the implementation of the Supporting People programme, some of which has illustrated both the importance of this initiative for meeting lower level support needs and the difficulties the programme has had including people with more complex needs (Griffiths, [Findings Ref. 080](#); Watson et al., [Findings Ref. 373](#)). It would seem to make sense for individual budgets to include this programme, particularly as a way of bringing together different sources of funding for people with higher levels of support.

**Recommendation:** Supporting People resources should be included within individual budgets.

## Consultation Question 11: Views on care navigator/broker model

The Foundation funded some of the earliest research on the value of service brokerage. This research defined service brokerage as:

'a method of allocating and using public funds for people who require social services which aims to increase their choice and control. It involves individualised funding, by which a negotiated sum of money is placed under the control of the user; and a service broker, who gives advice, information and practical help to the user. The model is based on a strong commitment to the rights of disabled people.' (Dowson, [Findings Ref. SC4](#))

Other Foundation-funded research found that [service brokerage has been particularly useful in enabling people who have significant cognitive impairments to use direct payments.](#)

We are concerned that the terms, and definitions, of 'care navigator' and 'care broker' used in the Green Paper (page 36) do not reflect the user-led development of service brokerage. Service brokerage has at its heart the promotion of choice and control for the person needing support. It is important that a similar commitment to the promotion of self-directed support is integral to the development of the role of broker/navigator. Such a role will also be key to introducing individual budgets if this is to be done in such a way to deliver choice and control for people who need support.

In terms of the question of whether the development of a service brokerage model might free social worker expertise 'to deal with the most complex cases' (page 37), it is certainly the case that service brokers do not need to be qualified social workers. However, it is also the case that those people who the Green Paper refers to as 'the most complex cases' would also benefit from service brokerage and it is important that people with complex needs are not denied access to this mechanism for promoting choice and control.

In terms of the skills needed to perform the function of a service broker, the core skill required is the ability to enable the views of the service user to dominate the process of putting in place responses to their needs. Service brokers should be committed to promoting choice and control for people who need support.

**Recommendation:** The promotion of choice and control must be integral to the development of a service broker/navigator role. Service brokerage should also be made available to those with more 'complex' needs and lessons learnt from current use of service brokerage with people with learning disabilities.

**Chapter 6, Consultation Question 12: What do you think will be the impact of shifting the balance of services from high-level need to earlier, preventative interventions on the eligibility criteria and what this might mean for FACS?**

Older people would welcome a shift towards 'earlier, preventative interventions', although they would not generally use such language, preferring instead to refer to 'that bit of help' to enable them remain independent.<sup>3</sup>

Research found that [older people defined personal and domestic assistance as help, not care](#). They wanted services which supported them to care for themselves. Being looked after meant loss of independence.

Other research funded by the Foundation concerning, for example, people with physical impairments and people with mental health problems, also confirms that people would welcome help at an early stage. This is especially true for some parents with learning disabilities, or mental health problems, who are at risk of losing their children into care if they are not given practical support at an early stage. There are real problems caused by the high eligibility thresholds set by adult services.

Currently, resources are targeted on those people with the highest levels of need (15 per cent the older population, for example). However it is hard to see how there can be a reduction in services to those in greatest need. Few, if any, social services authorities are managing to meet more than the Critical and Substantial levels of needs as laid down by Fair Access to Care Services. Meeting lower levels of need may – in some case – prevent higher levels of need arising but this will only lead to a reduction in the numbers of people with higher levels of need in the medium to long term.

**Recommendation:** There is widespread support among older and disabled people for access to services at lower levels of need, including preventative services. We therefore strongly support the idea that resources should be put into 'earlier, preventative interventions' but believe that this will require an increase in resources for social care, particularly in the short term.

## **Chapter 8, Consultation Questions 16–18: Strategic commissioning, shift to prevention, and partnership working**

We broadly support the proposals set out in Chapter 8: research would indicate that a shift towards more universal services, earlier interventions and partnership working between different agencies is more likely to achieve older and disabled people's aspirations for choice and control and social inclusion. Older and disabled people, and their organisations, must be part of such strategic commissioning and collaborative working. Research also tells us that [information, advice and advocacy are central to shifting the current emphasis](#) from one of rationing welfare services to one of promoting well-being, based around a citizen-led rather

than client-focused approach.

## **Chapter 9, Consultation Question 19: What help and support do local authorities and other social care providers need to work with people using services and carers to transform services?**

One of the most important issues highlighted by the Foundation's Older People's Programme was the way that [policy is made, and services designed, by people who do not use such services](#).

Similarly, a research project carried out by people with learning disabilities also found that people [who use day services are rarely involved](#) right from the start when decisions are made about changing and developing services.

A wide range of research funded by the Foundation has clearly demonstrated that services cannot enable people to achieve their aims and aspirations without the full involvement of services users. The involvement of service users, and potential service users, in setting the policy agenda and in designing services is therefore key to achieving the outcomes that people value. Improving Life Chances committed the government to the development of User Involvement Protocols for each government department and local authority, and also to each locality having a user-led organisation (modelled on existing Centres for Independent Living) by the year 2012. It would have been useful to reiterate these commitments in the Green Paper.

**Recommendation:** The forthcoming White Paper should place the involvement of people who use social care services at the heart of policy making and the design, delivery and monitoring of services. The White Paper should also set out plans for the development of user-led organisations in each locality, modelled on Centres for Independent/Inclusive Living, by 2012 (following the commitment in Improving Life Chances).

## **Chapter 10, Consultation Question 21: Views on appropriate performance measures to encourage implementation of the vision**

The starting point for setting performance measures should be consultation with people who need support about what would be the most appropriate measures. The Foundation funded a project in Wiltshire which enabled users of direct payments to [design and carry out a Best Value review of direct payments](#). The outcomes to be measured were set by disabled people themselves and this project demonstrated the value of involving people who need support right from the beginning of any process of performance measurement.

**Recommendation:** People who need support should be involved in the setting of outcome

measures.

There is evidence of both historical and continuing unequal access to support among Black and minority ethnic disabled and older people. Recent evidence shows, for example, that [Black and minority ethnic mental health survivors are particularly excluded from mainstream services](#). Appropriate outcome measures for these groups should be developed in consultation with representatives of these communities.

**Recommendation:** Black and minority ethnic communities should be involved in developing performance targets to address the current unequal access to support among Black and minority ethnic disabled and older people.

## Chapter 11, Consultation Question 23: Workforce skills

Modernisation of the workforce and the promotion of strong leadership, are certainly important elements of delivering the 'vision' set out in the Green Paper. However, an understanding of the social model of disability and of the concept of independent living must be integral to improving the skills and capacity of the social care workforce. The Foundation has funded a considerable amount of research on the implementation of direct payments and other initiatives intended to increase choice and control for people who need support (such as Person Centred Planning). All this research (some of which is referred to above) has found that an understanding of disabling barriers and a commitment to promoting choice and control are crucial among social care workers at all levels. Without such understanding and commitment resources the goal of independent living will not be achieved.

**Recommendation:** An understanding of the social model of disability and of the importance of choice and control should be integral to the training of the social care workforce, and should be promoted by social care leaders.

One very important skill necessary in order to promote choice and control is the ability to enable people with significant communication and/or cognitive impairments to express their views. Research on the experiences of people with dementia has illustrated [both the importance of enabling them to communicate their views, and the training and support needed by staff in order to work in such person-centred ways](#).

[The importance of enabling people with significant cognitive and communication impairments to communicate their views](#) has also been demonstrated to be key to promoting their human rights. Research on the experiences of people with communication impairments following a stroke highlighted the extreme social exclusion which can result from a failure to acknowledge and understand communication needs. It found that [health, social and residential care](#)

[workers did not have training or information about aphasia](#), and did not know how to support fragile communication.

If the Green Paper is to deliver its vision for all those with support needs, it is very important that workforce training pays particular attention to the skills required to enable people with significant communication and/or cognitive impairments to exert choice and control.

**Recommendation:** Training on the skills needed to enable people with significant communication and/or cognitive impairments to exert choice and control should be a key part of the modernisation of the workforce.

## Chapter 12, Question 26: Increasing community capacity

We have already mentioned the importance of user-led organisations and how these are crucial to delivering the improvements that people want to see in social care.

Some of the most important services provided by the voluntary and community sector are advice, information and advocacy services. The JRF Task Group on Housing, Money and Care for Older People highlighted that [improvements are needed to the provision of information, income maximisation and other advice and advocacy](#) to enable older people to have greater choice and control in older age, especially at key points of transition in their lives.

**Recommendation:** Local Strategic Partnerships should, in partnership with local community groups, develop comprehensive strategies for the provision of information, advice and advocacy services. Government should recognise the resource implications of implementing such strategies.

Consultation with Black and minority ethnic communities has highlighted [the value of voluntary organisations within these communities](#). Such organisations experience insecurity, however, because of short-term and inadequate funding, and (sometimes) a failure of funding bodies to recognise their value. There is also a need to [build capacity among communities and individuals](#) in order to promote strong organisations and good quality services. )

**Recommendation:** Local Strategic Partnerships should be encouraged to develop the capacity of Black and minority ethnic community organisations and commissioners should recognise the value of the services provided by these organisations to local communities.

## Inclusion of older people

We welcome the emphasis made in the Green Paper on the contribution older people can make in many different ways to their own lives, local communities and economies. Any further work should, [as our Inquiry did](#), involve older people working with commissioners and designers of provision.

**Recommendation:** set up a national older people's unit co-ordinating activity across all government departments, with full participation from older people. Additionally, there is a need to support better older people and their carers to navigate the complex care system.

## Definition of 'disabled person'

Improving Life Chances committed the Department of Health to consulting on replacing the 'current definition of "disabled person" for the purposes of community care services that is consistent with the DDA definition and takes account of the implications for disability across all ages'. It would have been useful if the Green Paper had been used as an opportunity to carry out this consultation.

**Recommendation:** The Department of Health should implement its commitment to consulting on replacing the current definition of 'disabled person' within community care legislation.

## The 'right to request'

Chapter 4 says that the government has decided to 'consult specifically on the merits of a "right to request" not to live in a residential or nursing care setting... This "right to request" would require service providers to make explicit the reasons behind their decision to recommend residential care, including cost considerations' (para. 4.17). However, there does not seem to be a consultation question relating to this.

The Joseph Rowntree Foundation believes that disabled and older people should have an entitlement to independent living. Choice and control over any assistance required is key to independent living and for many this will also mean that they want to live in their own home. The structure and resourcing of social care should not force people to leave their home in order to get what assistance they need. As the Task Group on Housing, Money and Care for Older People pointed out, [older people with their own resources do not have to move to a care setting to get care on a 24-hour basis](#), or move to sheltered housing because they cannot get their grass cut or their house cleaned.

In contrast, those who do not have sufficient resources may have no option but to move into a residential setting because their local authority will not fund home care support above a

certain level. Research has consistently found that this can happen against the older person's preferred wishes.

**Recommendation:** Disabled and older people should have an entitlement to choose to remain living in their own home.

## Notes

1. **Facing the cost of long-term care: Towards a sustainable funding system** by Donald Hirsch, to be published by JRF on 12 September 2005.
2. **People, plans and practicalities: Achieving change through person centred planning** by Pete Ritchie, et al., SHS Trust 2003, supported by JRF.
3. H. Clark, S. Dyer and J. Horwood, 'That bit of help': **The high value of low level preventative services for older people**, The Policy Press for the Joseph Rowntree Foundation, 1998.