

Response to the Department of Health consultation

Liberating the NHS: Greater choice and control

Submission by the Joseph Rowntree Foundation

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The Joseph Rowntree Foundation (JRF) is pleased to submit the following response to the Department of Health's consultation on *Liberating the NHS: Greater choice and control*. We would be happy to supply any further information as required.

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

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Introduction

JRF welcomes the government's focus on greater choice and control for those who use the NHS. If carefully planned and resourced – for example, through accessible information, advocacy, training, and staff time – this should help to ensure that marginalised groups have greater voice and power, and that they can access the services that are most likely to support their health.

Although only a few JRF studies have focused directly on health services, much of our work on social care and independent living is highly relevant to this consultation, particularly given the expectation that social care, health and public health bodies should work increasingly closely together. In our response we have drawn out the key issues and learning which are transferable. We also refer to a number of studies that highlight the ignorance and discrimination specific groups can face, and the actual or potential effect of these on their access to healthcare.

Below we have selected from your consultation document those questions to which we are most able to contribute useful and relevant evidence. These focus on: choice, control and personalisation; end of life choices; training and education; having a say. The issues we would like to highlight are:

- the importance of listening to service users/ patients;
- the need to involve users/patients in commissioning of services;
- barriers and facilitators to the uptake of direct payments, especially by marginalised groups;
- the importance of palliative social work in helping people to make decisions at the end of life;
- the need for care home residents to be able to end their lives there;
- the need for professionals to have much better understanding of diversity and equality issues, and of the complexities of coping with multiple impairments;
- the need for better communication skills;
- the importance of skills and advocacy in supporting disempowered groups.

Choice, control and personalisation

Q1. How should people have greater choice and control over their care? How can we make this as personalised as possible?

There is a significant body of JRF work on the issue of choice and control. Our evidence is that the people who depend on services must be at the heart of decisions about their design and delivery. Our recent major project within our Independent Living programme 'The Standards We Expect (Glynn *et al.*, 2008), started from that position, by asking service users themselves what person-centred support is, what gets in the way of providing it and what helps. They identified numerous barriers, most of which will be highly relevant to the planned personalisation of health services. The barriers included:

- inaccurate assumptions about what people want
- inflexibility
- lack of information on options
- money and resources
- charging policies
- staff time and approach
- risk and regulations
- communications
- culture and language
- institutionalisation
- eligibility
- geographic inequality
- transport
- ageism
- negative experiences of user involvement.

Both direct payments and user involvement in commissioning have a key role to play in choice and control. Although these are not directly covered in this consultation, our research has something to say about both of these.

If those commissioning services are to be sure of promoting and protecting human rights, in the context of a commitment to personalisation, it is essential that service users are themselves involved in the commissioning process. But our current evidence (Mauger *et al.*, 2010) is that the involvement of service users in shaping local services is still in its infancy, with the definition of 'user involvement' varying from

one-off consultations to equal partnerships. There are some examples of better practice in social care, but in this study few were identified in health services. Commissioners and their partners were often poorly placed to engage with user involvement in commissioning, with limited skills, knowledge and practice of effective involvement. Even where they had knowledge, there were few drivers that pointed them towards service users and away from simply responding to organisational necessities. In most cases the facilitation of user involvement was handed down to voluntary organisations, without acknowledging tensions between their provider and advocacy roles or taking into account variable user involvement within voluntary organisations themselves. There seemed to be two ideas within the same system: while individual service users were to have choice and control in line with personalisation, commissioners retained control over block contracts, and it was difficult to see how one influenced the other. This study concluded that the ways services are commissioned pose challenges and opportunities for commissioners as well as users.

Direct payments and personal health budgets for healthcare are currently being piloted, and these offer an obvious way to help create a more personalised NHS, by giving people more control over their care. In social care, direct payments and personal budgets are certainly seen as one way of increasing the choice and control that people have over the support they receive. While we are very supportive of this direction of travel, our research shows that some groups find it hard to use these. For example, one study (Newbigging and Lowe, 2005) discussed the low take-up of direct payments by people experiencing mental health problems with more than 250 service users and staff. It identified what needs to happen for direct payments to be successfully implemented:

- Service users, carers and professionals need straightforward, accurate and accessible information about direct payments that is specific to mental health.
- Both service users and professionals can be confused about the distinction between access to an assessment for receipt of direct payments and access to services, where the threshold may be much higher and based largely on clinical considerations. This can affect take-up.
- Mental health service users require specific advocacy and practical support to facilitate access to and use of direct payments.

- 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.
- Ways to increase take-up by people from black and minority ethnic communities include developing resources and approaches, including outreach and direct support services specific to those communities.
- A change in the culture of mental health service provision is required. This would need a tangible commitment to promoting self-determination, evident in the way staff interact and support people experiencing mental distress.
- Introducing direct payments requires effective leadership to drive the process of implementation from national direction and guidance through to local leadership, at both a strategic and operational level.
- Fostering partnerships across organisations and supporting collaborative problem-solving could facilitate learning about the implementation of direct payments.
- Introducing direct payments in a planned way requires thought as to how existing services can be reviewed, reconfigured and recommissioned.
- 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.

Our work on people from BME communities (Chahal and Ullah, 2004) shows how few BME disabled people even knew about direct payments schemes. Poor knowledge of entitlement and information about services was not simply because of a language need. In one study all the participants were fluent in the English language or in British Sign Language and still lacked appropriate information (Vernon, 2002). An end outcome of poor knowledge of services and entitlements was that many gave up trying to get a service. Although carried out some years ago, this learning from social care direct payments could be useful in relation to personal health budgets. Service providers will need to identify how they are publicising their services and initiatives to reach a broad range of communities, taking into account language and cultural issues pertinent to the communities.

A more recent study on personalisation and rough sleepers (Hough and Rice, 2010) has a positive message about the potential and value of personal budgets for some of the most marginalised people whose lives are particularly chaotic, with messages about the importance of having a good support worker.

End of life choices

Q13. What choices are most important to people as they approach the end of their lives? What would best help to meet these?

Q14. We need to strengthen and widen the range of end of life care services from which patients and carers can choose. How can we best enable this?

Our research on palliative/ end-of-life care (Beresford *et al.*, 2006) has identified the dominance of medical approaches in this area. Those people who are able to access support, counselling and information through a specialist palliative care social worker value this service hugely, and find it increases their ability to cope with the medical aspects of illness. Service users from black and minority ethnic backgrounds have found that specialist palliative care social workers are very responsive to their problems around poverty and inadequate housing.

It is not only those living at home, but also residents in care homes, who want the choice as to whether they can end their lives in the home as opposed to in a hospital ward (Wild *et al.*, 2010). However, care home managers have identified a shortfall in funding once a resident's needs increase near to end-of-life. If the added cost of staff time required cannot be met by the resident or absorbed by the home, this cost is shifted to the health service through hospital admission or transfer to a nursing home. This works against integration and the rights of older residents. More flexibility around access to special end-of-life resources and funding would resolve this problem and maximise choice at end-of-life for those living in care homes. More flexibility in skill mix in care homes can also enable residents to stay put – with the additional potential benefit of cost savings (University of the West of England, Bristol and the University of Warwick, 2008a).

Training and education

Q27. How could training and education make choice and shared decision-making a part of healthcare professionals' working practices?

Our evidence suggests that healthcare professionals will need substantial training and awareness-raising on diversity and access issues, and in communication skills. If staff are really to understand the perspective of service users, they need to be offered training by service users. Staff who are also service users (for example of mental health services) have a key role to play here (Lindow and Rooke-Matthews, 1998).

If people are to have greater choice and control over their care, service providers need to understand that some have less power and voice than others. They will need to be sure they will not be discriminated against if their needs are known, and that there is an understanding that they may have specific needs. Below we have highlighted several examples of groups for whom this is highly relevant: older people living in their own homes; people with both physical and mental health problems; older people with HIV; and people with dementia (including those who also have a learning disability).

Older people may have different priorities to other age groups regarding healthcare services. We know that those living in their own homes value responsive health services such as more regular check-ups for those over 75; the regular review of repeat prescriptions; prescription pick-up and delivery services; and services that can help them get treatment at home when they are ill (Raynes *et al.*, 2001) .

People with both physical impairments and mental health support needs have tended to be overlooked by both policy-makers and those commissioning services. They often have difficulty accessing mental health services because of their physical impairments, and difficulty using physical disability services because of inadequate recognition of mental health needs and negative attitudes among staff towards mental health issues. In one JRF study inpatients often experienced inaccessible physical environments and a lack of assistance for even simple things (Morris, 2004). There was a lack of understanding of the assistance that people needed, and staff were often too busy to provide it. Medication required for a physical condition was commonly withdrawn on admission to a psychiatric ward and was not always available when needed. This caused considerable distress, particularly when the medication was required for the control of pain. Community mental health services were appreciated when needs relating to physical impairment as well as mental health were addressed. However, this was unusual. Staff were often unfamiliar with needs relating to physical impairment and this could be associated with unhelpful attitudes. There

was commonly poor or no communication between mental health and physical disability services. Many respondents found that services accessed because of physical impairment ignored mental health issues; some staff had negative reactions to such needs. Medication given for mental health needs often had an impact on physical impairment, but most people said they had not been warned about these potential effects. 'Talking treatments' received the highest rating of any service, but it was often difficult to find an accessible and, within the private sector, affordable therapist or counsellor. When people were asked what they wanted from mental health and physical disability services, they said they wanted to be seen as 'a whole person', with attention paid to both mental health needs and those relating to physical impairment. They wanted services and professionals to communicate and work together, and easy access to flexible services which could address individual needs. Above all, they wanted to be listened to and treated with respect.

We know too from JRF's study of older people living with HIV, the first in the UK, (Power *et al.*, 2010) that users/patients who have HIV – and particularly gay men – fear discrimination in services. One in five in the study had experienced age-related or HIV-related discrimination in the past year, with HIV discrimination worst in healthcare and goods and services. Yet this group report twice as many other long-term health conditions, which can complicate and exacerbate their often poor health. Those with the virus live with high levels of uncertainty about their future health and their highest priority in old age is good quality health and treatment information. Many of their conditions could be improved if better management of lifestyles, including nutrition, smoking and exercise, were included within long-term condition management. While they thought highly of their HIV clinicians, many reported poor experiences in primary care. For older people who are also living with HIV, relationships with GPs and other healthcare workers need to be as strong and as positive as those they report with their specialist HIV doctors. Yet respondents repeatedly told stories of discrimination, ignorance and poor clinical treatment in generalist healthcare, particularly in primary settings. This was despite high levels of disclosure to their GP – and generally positive outcomes from this. This finding mirrors the US experience: there they have begun to bring HIV clinicians, geriatricians and other physicians together to share expertise and improve practice. The finding that primary care is not serving people with HIV well is not a new one; but for older adults with HIV it is a more pressing problem than for others, and one which will impact on their health and longevity if not tackled. There is a strong and urgent need for

leaders in the medical profession and the NHS to challenge and change poor treatment.

One of the key barriers to enabling choice and control for people with dementia is communication. Research on their experiences points to the training and support needed by staff to work in person-centred ways and to enable people with communication and/or cognitive impairments to exert choice and control (Allan, 2001). The Talking Mat (Murphy *et al.*, 2007) is one evidence-based tool with important potential in communication and choice-making with people with dementia, potentially extending the period during which people can play an active role in making decisions about their lives. Staff will need to be trained and confident in using Talking Mats (or other tools) to achieve this.

People with learning disabilities who have dementia find it very hard to make health professionals and others aware of their symptoms and their pain (Kerr, 2006). Staff attitudes towards, and experience of, 'behaviour that challenges', problems around communication, beliefs about pain thresholds, the impact of past treatment of some people with learning difficulties on their willingness to complain of pain, and the use of agency/bank staff can all contribute to a low level of pain recognition. Sometimes staff are not sufficiently aware that people with learning disabilities who are getting older will experience the painful conditions, such as arthritis, that can accompany older age, nor are they fully aware of how these might affect someone with learning disabilities. There is inadequate training of staff at all levels in all professions about dementia and learning disabilities and, in particular, about the pain management needs of people in this group. There is also little use of pain assessment tools. Our evidence has identified a range of unsatisfactory practices among many GPs who had no specialist interest, and has highlighted a need for GPs to develop specialist skills. It suggests that interventions by GPs could also be improved by including issues relating to learning disabilities in undergraduate and post-qualifying education for GPs.

Having a say

Q18. How do we make sure that everyone can have a say in their healthcare?

Q19. How can we make sure that people's choices can reflect their different backgrounds – whether ethnic, religious or any other background that could affect their healthcare preferences?

Q29. What help should be available to make sure that everyone is able to have a say in their healthcare?

Our research shows that marginalised groups – for example minority ethnic groups, people living in poverty, people living in institutional settings such as care homes, and people with learning disabilities – will need information, advice and advocacy to help and empower them to choose the best services for them. But these are not always adequate, accessible or universally available.

Minority ethnic groups are a particular priority. Older people in a Bradford study gave examples of ageist attitudes and assumptions about ethnic communities among GPs, in hospitals, and in care homes (Cattan and Giuntoli, 2010). BME older people did not expect care staff to replicate all behaviours relating to their cultural or religious beliefs, but they did want respect and dignity. Potential barriers and factors that may restrict minority ethnic people from using health services were identified at three levels:

- patient level – these barriers relate to patient characteristics e.g. age, gender, ethnicity, lifestyle;
- provider level– these barriers relate to provider characteristics, such as medical procedures and practices, communication style, skills and translation;
- system level– these barriers relate to the organisation of the healthcare system, such as referral systems, the medical paradigm and organisational factors.

Another JRF study found that mental health advocacy has failed to reflect and address the specific needs of black and minority ethnic communities (Rai-Atkins *et al.*, 2002). It highlighted persistent problems in mainstream services that position black service users on the margins with limited support. Both black and white advocates felt that service users often suffered in isolation in the community, not knowing that advocacy services existed. Black and minority ethnic service users and their carers felt most empowered when they had an advocate reflecting their culture, gender and ethnicity. A third study, of Pakistani, Bangladeshi, Ghanaian and white English working-age people living with long-term ill-health, found that many respondents lacked coping skills and felt little control over their situation (Salway *et al.*, 2007). It was common for people in all four ethnic groups to conceal their ill-health, and so delay or refuse help, due to strong societal pressures to be 'normal'. Effective professional support was generally lacking. Minority ethnic respondents seemed particularly disadvantaged; while limited

English language competence was a problem for some, there were general feelings of exclusion from mainstream society and services.

People living in poverty also have reduced access to, and choice about, health services due to attitudes of staff. Mental health services are a key support mechanism for people suffering the effects of isolation and poverty, but participants in one Scottish study complained about the quality and availability of these services (Green, 2007). *GPs say: 'Go away, the only thing that's wrong with you is that you don't know how to cope. Now go away, I don't want to see you again'*. While some participants said their GP did not know how to deal effectively with mental health problems, others were positive about the practice of referring people to leisure services to help relieve problems.

People living in institutional settings can also be very disempowered in terms of making their own choices. A study of older people living in care homes found that their voices are largely absent; other people (professionals, families) speak for them, and they are 'perceived as commodities, not as consumers or citizens with rights, entitlements or purchasing power' (Bowers *et al.*, 2009). Health professionals are often powerful in making decisions for people, even in relation to non-health services – for example, they can make older people feel they have no choice but to go into a care home. A JRF literature review found that medical cover for care home residents is sub-optimal, and that any partnership working between district nurses and care home staff appears largely to occur by default (University of Warwick, University of the West of England, and University of York, 2008b).

There is also evidence that better management of medication is needed in nursing homes. Pharmacist reviews of medication can have a positive effect. Providing basic health skills to front-line care staff can also improve awareness of health issues at an earlier stage (Wild *et al.*, 2010). Care home staff need enhanced personal skills and support from healthcare professionals to meet these needs. Health-orientated education and training of care staff can be successful, leading to increased confidence and professionalism in care staff and stronger relationships with community nurses and GPs.

Research has found that decision-making by people with learning disabilities is hampered by many factors, including negative assumptions that people could not make choices; organisational systems and structures that reduced choices to a fixed menu; poor staffing levels and low awareness of supported decision-making; service cultures and staff

fears that set aside people's wishes and feelings where there were contentious issues or perceived risks; lack of independent advocacy; concerns about the law around decision-making and capacity, and lack of knowledge about legal rights and systems (Glynn *et al.*, 2008). However, they also found ways of working that actively facilitated the 'supported decision-making' model, particularly around good communication and relationships; a focus on the process of decision-making, rather than on assessments of capacity to decide; and a rigorous approach to building evidence of the process, including careful and creative recording and monitoring. The researchers concluded that advocates, managers, staff and family members need better information about the supported decision-making model and people's legal rights and entitlements.

On this final point about the interface between choice, control and legal rights and entitlements, we note, and look forward to, the outcomes of the current Law Commission review of adult social care legislation. Our understanding is that this will seek to provide greater clarity about the legal distinctions between health and social care. We recognise this is incredibly difficult – not least because the existing legal and administrative boundaries between health and social care are blurred and seldom conform to how people see themselves and their own lives. However, we note it here as the outcome of the Law Commission's work will clearly have a bearing on the direction of travel by the NHS in relation to health and social care, and in relation to choice and control for users of health and social care services.

Conclusion

JRF welcomes and broadly supports the new focus on greater choice and control for users of health services. That said, we would like to see a much stronger emphasis on:

- improving real understanding among health staff of diversity, equality and empowerment issues – and of the potential barriers to access and real choice;
- the need to invest in information, advocacy and training;
- the importance of listening and communication skills (both general and in relation to specific groups or conditions);
- involving users/patients in commissioning of services.

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