

# Response to the Law Commission Consultation on Adult Social Care

Submission by the Joseph Rowntree Foundation

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The Joseph Rowntree Foundation (JRF) is pleased to submit the following response to the Law Commission's consultation on creating a simple, consistent, transparent and modern framework for adult social care law. 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 search, demonstrate and influence, providing evidence, solutions and ideas that will help to overcome the causes of poverty, disadvantage and social evil.*

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## **Introduction**

JRF welcomes the overall goal of the Law Commission to streamline and clarify existing social care legislation. Research from a wide range of JRF-supported projects exploring service users' and carers' experiences and perceptions of the care system identifies its complexity as a significant source of frustration and distress for people.

Any attempt to clarify the system for service users, their families and care professionals is to be welcomed. To this end, the Law Commission's attempt to bring together a single statute with a set of defining principles and rights, definitions and processes, and a single code of practice, is a vitally important endeavour. JRF therefore firmly supports the Commission's provisional proposal 2-1 to create a single statute and, in response to question 2-2, agrees that the Secretary of State and Welsh Ministers should have a duty to prepare a code of practice to bring together statutory guidance.

The following document outlines JRF's response to some of the specific provisional proposals and questions posed in the Law Commission's document.

## Summary

JRF welcomes the Law Commission Consultation on Adult Social Care legislation and is very supportive of its aims and focus in clarifying social care law for users, their families and practitioners. However, there are a number of issues which may have been overlooked and which, based on JRF's research and practice, deserve greater prominence. In summary, these are:

### ***The user voice***

JRF is surprised to see that the voice of people who use social care services in defining and planning their own care and support, and indeed in drafting social care law itself, has not been fully taken into account. The Commission's focus on choice and control and person-centred planning is welcome but there needs to be more explicit reference to the views and preferences of service users actively setting the agenda for social care and support.

### ***Human and civil rights***

JRF is concerned by the lack of explicit reference to Human and Civil Rights in the proposed statute. Whilst accepting that the statute's duties need not duplicate the provisions of the Human Rights Act, Disability Discrimination Act and others, JRF does feel that the statute should reaffirm *the attainment and protection of human and civil rights within the context of adult social care* as the founding principle on which this new statute is based. All other proposed principles outlined in this document can be seen as a means to this end.

The Commission may also want to consider reflecting within the new social care statute the increased legislative, political and cultural focus on the concept of rights and responsibilities, active citizenship and individual empowerment (Brindle, 2008). The language of care should, as the Commission points out, shift from one of services to one of needs and outcomes. But alongside this must be a shift in the narrative from passive service recipient to active and engaged citizens who are in command of their own life choices. This is missing from the current language of principles and definitions of community care and care users.

### ***Outcomes and needs***

In spite of the Commission's endeavour to create, through the statute's principles, a more person-centred approach to care, which includes a focus on needs and outcomes rather than services, there are points in the document where a service-based approach remains. These include

attempting to establish a prescribed list of *services* to be used in the definition of community care; the proposed concept of a service user being defined by eligibility to *services* rather than needs; and a duty for social care to cooperate with a pre-defined and specific list of services outside of social care. In each of these cases, JRF has proposed an alternative based on outcomes and needs (not on services) which would be more in keeping with the proposed principles for the statute as set out in Part 3 of the Commission's document.

### ***Information, advice and advocacy***

JRF welcomes the Commission's proposal to place a duty on a local social services authority to provide information about services available in the local area. However, JRF research and consultation with service users has found that information alone is often inadequate, and there is a real need for information, advice and advocacy. Advocacy – including peer advocacy and collective advocacy through user-led organisations – is essential if both a) information and advice and b) personalised care and support are to be delivered, effective and meaningful to people using services and their families (Godfrey *et al.*, 2004; Horton, 2009).

## **JRF response to provisional proposals and questions**

### **Our approach to law reform (Part 2 of the consultation paper)**

***Question 2-3: Is our process-driven approach to adult social care (a prescribed assessment and eligibility process, with support from prohibitions, a broad list of services, care plans and statutory principles) sufficient to determine the scope of adult social care, or is further definition required?***

JRF believes a combination of statutory principles; processes (assessment and eligibility and co-produced planning based on needs and outcomes); prohibitions combined with a duty to cooperate with all relevant services; and an open, outcome-based and user-based definition of community care will be sufficient to define the scope of adult social care in a person-centred, rather than a service-centred way.

### **Statutory principles (Part 3 of the consultation paper)**

***Provisional Proposal 3-1: We provisionally propose that our future adult social care statute should include a statement of principles.***

JRF supports this approach, agreeing with the Commission that a statement of principles enshrined in law will help promote the consistent application of legislation and much needed clarity, and may enable service users to feel more confident about demanding compliance with them. A statement of principles should begin with, and be framed by, explicit reference to the role of adult social care in promoting and protecting human and civil rights and entitlements.

***Question 3-1: Should there be a principle in our proposed adult social care statute which provides that decision-makers must maximise the choice and control of service users?***

JRF strongly agrees that choice and control should be a principle included in new social care law. This principle should also emphasise the central importance of the *user voice* and *user involvement* (“Nothing about us without us”).

The principle of choice and control could be reworded to reflect the evidence from our projects and programmes, which shows that people

have a right to be involved in decisions about their lives and that most people are able to do this in a number of different ways. Possible wording could be: *'people have a right to be involved in decisions about their lives and professionals must therefore maximise people's voice, choice and control to this end.'*

JRF's research clearly demonstrates that without the service user being able to express their views and preferences, they will be unable to exercise choice and control. Unless user voices are listened to by carers, professionals and commissioners, choice and control remains an empty exercise (Mauger and Deuchars, 2010; Bowers *et al.*, 2009)<sup>1</sup>.

A number of JRF studies show that communication and participation in decision-making and informed consent can be supported with people who have high-level support needs, including significant cognitive and communication impairments (Edge, 2001; Allan, 2001; Murphy *et al.*, 2010; Bowers *et al.*, 2009). JRF studies also highlight the barriers in achieving this (for example: Glynn and Beresford, 2008; Bowers *et al.*, 2009; Mauger and Deuchars, 2010; Older People's Steering Group, 2004).

In light of these findings, a principle which recognises the fundamental importance of user voice in achieving choice and control, and which enshrines in statute the need to facilitate and take into account service users' voice would be extremely useful.

***Question 3-2: Should there be a principle in our proposed adult social care statute based on person-centred planning – or should this be incorporated into other provisions of the legislation?***

JRF believes it is important that the concept of person-centred *approaches* (this includes but is not restricted to person-centred planning) is enshrined within the statute, located within or alongside provisions on voice, choice and control, and principles of independent living.

This position reflects JRF evidence that whilst person-centred planning has been widely endorsed (particularly in relation to people with learning difficulties), it has not as yet been fully adopted or implemented across adult social care services. It has proved easier to talk about it than to do it. Service users often feel that they have little impact on the way that services are planned and delivered (Mauger and Deuchars, 2010).

Obstacles to person-centred planning – and more broadly to person-centred approaches to supporting people – include lack of resources, culture and attitudes of carers and families, skills and training of staff and poor inter-agency working (Glynn et al 2008). There are clear calls for more control on the part of service users and their families (Dowling *et al.*, 2006), and for greater recognition of the role of peer support and advocacy organisations led by service users in making person-centred approaches happen (Branfield and Beresford, 2006).

***Question 3-3: Should there be a principle in our future adult social care statute which provides that a person’s needs should be viewed broadly?***

***Question 3-4: Should there be a principle in our proposed adult social care statute based on the need to remove or reduce future need?***

JRF would like to see one combined principle in the statute which provides that people’s needs and desired outcomes are central to any assessment or planning, with a clear implication that this would include ‘need’ in its broadest sense, that is: covering higher *and lower level/preventative needs*; as well as covering needs which include but also go beyond the areas outlined by the Department of Health and cited in the Commission’s paper (personal and social care; health care; accommodation; finance; education, employment and leisure; and transport and access).

On low-level and preventative support: JRF’s Older People’s Inquiry into this issue found that there was a significant and unmet demand among older people for ‘that bit of help’, which the inquiry members chose to use as a phrase in preference to the professional term ‘low-level services’ (Raynes *et al.*, 2006). Relatively low cost, and often mainstream, universally accessible services were identified as having disproportionate benefits to people’s sense of independence and wellbeing and as a means of preventing more costly and intensive help later on (Raynes *et al.*, 2006). The value of preventative services has also been highlighted in research exploring the provision of nursing and physiotherapy support in residential care homes for older people (Wild *et al.*, 2008; Wild *et al.*, 2010).

Preventative services are not the same service in smaller portions at an earlier stage. One study involving older people found:

It should be about equipping people with the skills, coping techniques and circumstances to remain independent. It's as much about learning how to use a computer, pursuing an active lifestyle or ensuring a safe neighbourhood, etc., as it is about providing one hour of home care per week. It's a responsibility that extends well beyond social services.  
(Clough and Manthorpe, 2007).

It has been accepted by policy-makers and user groups for some time that people's needs should be seen in a broad sense (Turner, 2003). Strategies such as *Our Health, Our Care, Our Say* include the importance of 'making a positive contribution' and 'personal dignity' whilst the Independent Living movement of disabled people has developed a list of needs which include:

- appropriate and accessible information;
- an adequate income;
- appropriate and accessible health and social care provision;
- a fully accessible transport system;
- full access to the environment;
- adequate provision of technical aids and equipment;
- availability of accessible and adapted housing;
- adequate provision of personal assistance;
- availability of inclusive education and training;
- equal opportunities for employment;
- availability of independent advocacy and self-advocacy;
- availability of peer counselling<sup>2</sup>.

The areas of need cited in the Commission's paper seem narrow and service-based in comparison.

Within JRF's Older People's Programme, an initial investigation by Bowers *et al.*, (2002) in a two-day participatory conference with older people highlighted older people's own priorities:

- valuing diversity;
- continuing to learn;
- being active, staying healthy and contributing;
- the importance of family and relationships;
- friends and community, being valued and belonging;
- having choices, taking risks;
- approachable local services.



These were refined into the *Keys to a Good Life*, which include the need to maintain and develop friendships and social relationships, a meaningful community life, and maintaining personal identity and self-esteem (Bowers *et al.*, 2009). These, as well as recognition of the importance of family life, all need to be included into a broad definition of need. This last point is particularly important given JRF findings regarding service users who are also parents, who often find it difficult to access appropriate services to support their parenting roles, given local authorities' very different interpretations of this as either part of social care needs or completely disconnected (Olsen and Tyers, 2004; Morris, 2004b).

Given the existing levels of eligibility set in most local authorities, it may be very difficult to enshrine principles which specify that people's broader needs, and lower level/preventative needs, should be taken into account. Nevertheless, more outcomes-led and integrated support packages, spanning lower and higher level services, have now clearly been established as good practice and very much in the direction of progressive policy reform.

***Question 3-5: Should there be a principle in our proposed adult social care statute based on the concept of independent living?***

Independent living, as the 'philosophy and practice which empowers disabled people and enables them to exert influence, choice and control in every aspect of their life' (Campbell, quoted in Hasler, 2007, unpublished), has been an important principle over the last two decades in challenging discrimination based on disability and age. JRF would welcome a principle which reflects this within the statute.

Independent living as a concept and approach to commissioning and delivering support is not as well understood among older people, commissioners and service providers, policy-makers and leads focusing on older people's services. Nonetheless, consultation with older people does suggest they want to maintain their sense of independence, to minimise the impact of any physical limitations on their lives as a result of illness, health conditions or impairment; and they develop strategies to achieve this.

Independent living is less about doing things for oneself (the standard definition applied by existing policies and commissioning strategies) and more about choice and control over decisions, support, resources and lifestyles (Bowers *et al.*, 2009). Indeed, JRF's work with those with

learning disabilities generated a user-led definition of independence which very much reflects this – they stated that ‘Independence is about being able to make your own choices, deciding to take your own risks and having the support to take those choices. It is not about being able to do everything yourself.’ (Hart *et al.*, 2007). This interpretation of independent living is more inclusive, in that it can apply to those service users for whom independence (in the sense of living in one’s own home and doing everything for oneself) is not possible, but who can still exercise a degree of control over their lives.

**Question 3-6: Should there be a principle in our proposed adult social care statute based on an assumption of home-based living?**

JRF believes a principle based on the assumption of home-based care would be inappropriate for a number of reasons.

Firstly, the Commission’s assertion that: ‘An assumption in favour of home-based care is essentially a constituent element of independent living’ conflates *independent* living with *home-based* living. As outlined above, JRF believes a more inclusive definition of independent living is needed – one not based on location or on functions being carried out for oneself, but rather a definition based on the level of control and opportunity to make decisions and changes to one’s environment and day-to-day life. Institutional or communal living can also provide independent living in this form.

JRF’s research into extra care housing also demonstrates that semi-residential settings may provide independent living *more effectively* than home-based care. Residents in extra care schemes reviewed by JRF were found to enjoy a great degree of independence which was facilitated, rather than undermined, by the additional support on site being used as a safety net. Schemes could also provide residents with higher needs and who were receiving care services the opportunity to leave their home and circulate around the communal site with the support of care staff (Callaghan *et al.*, 2009), thereby giving them a greater sense of independence than they might have had living in their own home.

JRF’s study looking at independent living among those with learning disabilities also found that the residential units in the study gave those living there more independence than those people living with their parents. The residents reported: ‘We think that the Smith Homes community and other communities of this type are communities by

themselves. People have a lot of support. People could move if they wanted to but we found that most people did not want to. This is because they feel safe and at home.’ (Hart *et al.*, 2007)

Second, and as the Commission itself recognises: ‘it may be difficult to draft a principle in favour of home-based care, as there would need to be a clear distinction made between care being provided at home and care being provided in an institution. However, some housing can be described as both’. As people live longer with support needs, the distinction between home and institutional settings will become increasingly blurred. Hartfields, a retirement village owned by the Joseph Rowntree Housing Trust, demonstrates this. It is intended to be an independent living setting, but can accommodate people with high levels of need for care and support who would otherwise be living in residential care (Croucher and Bevan, 2010). A principle which sought to emphasise home-based care above settings such as Hartfields would rely on an increasingly blurred and artificial distinction.

Third, a principle favouring home-based care would be based on the assumption that all people with care and support needs *can* and *want* to live in their own home indefinitely. Older people in JRF’s Older People’s Steering Group commented that living at home wasn’t necessarily the same as living well, particularly if that person was isolated and unsupported.

The literature associated with residential care identifies conflicting views. On the one hand, there are many instances of a forced and unwelcome move to residential care (Bowers *et al.*, 2009). On the other hand, a move into a care home can also be seen as a conscious change of living arrangements, which can enhance personal feelings of independence. Given the very diverse needs and preferences of disabled and older people, favouring home-based care over other forms (residential, extra care, supported or shared living arrangements and so on) could perpetuate a one-size-fits-all approach to care provision and could be contrary to the principle of choice and control when a care user makes a positive decision to move from their home (a point the Commission recognises).

Analysis of the residential care market between 1991–2001 found that those areas which saw the greatest decline in residential care provision were not those where home-based care increased, but were instead areas where more people were moved to other local authorities’ residential care facilities (Banks *et al.*, 2006).

**Question 3-7: Should there be a principle in our proposed adult social care statute based on dignity in care?**

JRF research indicates that dignity and respect are key ingredients but also low aspirations on which to build a challenging agenda for government policy and best practice guidance on long-term care (Bowers *et al.*, 2009). What is required is an approach based on citizenship, with an increased focus on personal identity, self-expression and individual aspirations, rights and circumstances.

JRF evidence highlights the importance of involving service users in big and small decisions (e.g. Branfield and Beresford, 2006). There is a related need to recognise the impact of disempowering relationships, which have wide-reaching consequences for people who live in situations where their voices are effectively managed by others. This often arises as a result of other people's concerns and anxieties for them, but acts as a significant barrier to person-centred care (Bowers *et al.*, 2009; Glynn and Beresford, 2008).

**Question 3-8: Should there be a principle in our proposed adult social care statute based on the need to safeguard adults at risk from abuse and neglect?**

The principle of safeguarding adults at risk of abuse and neglect is clearly a vital element of any social care statute. JRF does not believe that the Commission's proposed duty (12-4) on local authorities to make enquiries in cases of abuse and neglect would render the inclusion of the principle unnecessary. The general principle to guide all practice is just as important as a specific duty, which does not fulfil the same role. Moreover, a duty to investigate after the event seems *retroactive*, which in itself is somewhat contradictory to the preventative, or *proactive*, concept of safeguarding. This pro-active approach must underpin the statute within its own principle.

JRF believes the principle should be underpinned by a wide definition of abuse – including not just physical and sexual, but also emotional and financial abuse and neglect. There should also be a recognition that older people make up the majority of adult abuse cases (Pritchard, 2000), and that men are also at risk and their cases should be treated equally by professionals (Pritchard, 2002). Enshrining safeguarding as a founding principle of social care, with an inclusive working definition of

abuse and neglect, will help to address some of the weaknesses uncovered by JRF research.

***Question 3-9: Should any one principle in adult social care be given primacy over all other principles?***

JRF would like to see the inclusion of an additional and more fundamental primary principle than those set out by the Commission: a primary principle to reaffirm *‘the attainment and protection of human and civil rights within the context of adult social care’*. All other proposed principles outlined in this document can be seen as a means to this end.

The duties and guidance of a new social care statute would not need to replicate the provisions of the Human Rights Act, Single Equalities Bill or the Disability Discrimination Act unless ‘an existing legal provision is relevant, but is not clearly stated or expressed in terms relevant to adult social care’. But this does not mean to say that a new statute cannot *reinforce* the importance of pursuing and upholding human and civil rights in an adult social care context.

This is important because the principles outlined in the Commission’s document – voice, choice and control, safeguarding etc. – can all be thought of as means to an end, with the end being the attainment and guaranteeing of human and civil rights. Older people and disabled people have themselves explained that they value involvement not *in and of itself*, but as a means to effect change and improvement (Reed *et al.*, 2006; Carter and Beresford, 2000). Even where an end is defined, such as independent living, this is still part of a wider concept of equal rights. Therefore, given that the attainment and guaranteeing of rights is already strongly implied within the proposed principles, it would seem odd not to make explicit reference to this.

Clearly balancing people’s right to freedom and choice with freedom from harm can be challenging in a social care context. However, having a principle which recognises the need for balance is important to ensure that choice, voice and control, independent living and so on are not subverted by overly risk averse and protective models of care. Being overprotective is ultimately unlikely to be helpful if people are to take more control of their lives (Glynn and Beresford, 2008).

There will inevitably be tensions. Users acknowledge that with certain impairments and in certain conditions people do not always act in their own best interests (Hart *et al.*, 2007). In such cases, the welfare

principle in the Children Act and perhaps even more so the best interest principle in the Mental Capacity Act could be seen as relevant to adult social care. The latter states: 'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.'

The principle of acting in the person's best interests will not preclude situations when hard decisions need to be made, but it can signal to those applying the law that these principles should be perceived *dynamically*, and that ultimately principles must always be used to make decisions in the best interests of the person concerned. Perceptions of best interest will sometimes differ; this is where skilled decision-making and arbitration can be enabled, rather than hindered, by legal principles.

### **Assessment (Part 4 of the consultation paper)**

***Provisional Proposal 4-1: We provisionally propose that there should be a duty to undertake a community care assessment in our future adult social care statute, triggered where a person appears to the local authority to have social care needs that can be met by the provision of community care services (including a direct payment in lieu of services) and where a local authority has a legal power to provide or arrange for the provision of community care services (or a direct payment) to the person.***

***Question 4-1: Should our proposed adult social care statute include a right to have an assessment on request?***

JRF is concerned that the triggering of an assessment based on whether a person 'appears to the local authority to have social care needs' could be very widely interpreted to include or exclude different groups, or be open to the influence of budgetary pressures. This would particularly be the case if the Commission's proposal 9-1 is implemented (i.e. to have a broad and short list defining community care) as this list is very much service-based. The appearance of need could well be conflated with the need *of a service*, which would render the Commission's proposal 4-2 (having an assessment based on need and outcome rather than service suitability) very difficult to implement. If the Commission's proposal 9-3 (not to include a definition of disability in the statute) were also carried forward, the right to an assessment would almost be exclusively based on local authority discretion with no guidance for local authorities on the groups of people most likely to require an assessment.

JRF research in two local authorities back in 1998 found that despite centralised guidelines issued by local authorities, different social work teams determined eligibility for assessment differently. The type of team with which disabled people had contact influenced their access to assessment. Most social workers' decisions about access to assessment were influenced by service criteria based on risk and linked to budget considerations. Disabled people and carers had wider definitions of risk, which practitioners appeared reluctant to recognise and respond to (Davis, Ellis and Rummery, 1998).

It is for these reasons that JRF strongly supports the idea of having a right to request a social care assessment, and moreover, that local authorities should be issued guidelines to raise awareness of this right.

***Provisional Proposal 4-2: We provisionally propose that the focus of the community care assessment duty should be an assessment of a person's social care needs and the outcomes they wish to achieve, and should not focus on the person's suitability for a particular service.***

JRF strongly supports this proposal. Consultations with service users and providers indicates that a narrow, service-centred approach undermines the entire principle of person-centred support (Glynn and Beresford, 2008), as people's needs do not always fit neatly into specific service areas.

JRF's *Shaping our lives* project (Turner, 2003) indicated that looking at outcomes from users' perspectives involves taking a holistic view, and considering issues such as housing, transport, employment, income and benefits, and broader issues around discrimination and equality. However, many users involved in this project felt that the services they dealt with did not acknowledge or value their own outcomes. Service users in another study valued the ordinary things in life – cleaning, shopping and support at home – but they found it very difficult to get services to prioritise support in these areas (Turner, 2003). This echoes earlier JRF work which found that the narrow reach of community care needs assessment left many people without access to support services particularly regarding preventative, housing-based strategies aimed at assisting people to sustain their accommodation or to set up in their own home (Watson, 1997).

Service users have clear ideas regarding what constitutes good quality of life, including many aspects which do not have a neat service fit. For example, personal identity and self-esteem, a desire for an 'ordinary life', social and intimate relationships, and a sense of belonging to and participating in communities and wider society have all been identified as important (Godfrey *et al.*, 2004; Bowers *et al.*, 2009).

A move to outcome and needs-based assessments would put the individual service user and their views, needs and wishes at the centre of the work, as the setting of outcomes is both a personal and subjective process (Turner, 2003). This would be more in keeping with the principles of choice and control and broad understanding of need as proposed in Part 3 of the consultation paper.

***Question 4-2: Should our proposed adult social care statute recognise co-produced self-assessments as a lawful form of assessment?***

JRF asks the Law Commission not only to recognise co-produced assessments as lawful, but to set out a *statutory duty* for authorities to co-produce assessments unless circumstances make this impossible.

Co-produced assessments are vital in ensuring users' voices are heard and their preferences and wishes taken into account, which, as outlined above, is fundamental to the exercise of choice and control. Co-produced assessments should therefore be standard practice in a care system based on choice and control and person-centred support. An assessment carried out *without input and involvement* would undermine the principles laid out in Part 3 of the consultation paper.

It is also difficult to see how the Commission's provisional proposal 4-2 (assessments based on needs and outcomes) would be feasible if service users were *not* central to assessments in defining needs and setting their own outcome. JRF research emphasises both that the setting of outcomes is subjective and personal and must place individual service users at the heart of the process (Turner, 2003) and that the process of determining felt need is most effective when it is an interactive process between citizens and services in a relationship of negotiation rather than one of provider and recipient (Godfrey and Callaghan, 2001).

JRF research suggests there is much room for improvement when it comes to engaging service users in commissioning and planning



decisions (Mauger and Deuchars, 2010); that service users feel prevented from making choices and setting goals due to professionals who ‘think they know best’ (Glynn and Beresford, 2008); that specific groups of service users – those in residential care or with higher level needs – often have their wishes and preferences overlooked (Bowers *et al.*, 2009); and that people with high-level support needs, cognitive or communication impairments can still participate in decision-making and provide informed consent (Edge, 2001; Allan, 2001), and there are a range of tools to support this (e.g. Talking Mats – Murphy *et al.*, 2010).

In light of these findings, a statutory duty to co-produce assessments would be an important step towards empowering service users.

### **Carers’ assessments (Part 5 of the consultation paper)**

***Provisional Proposal 5-1: We provisionally propose that there should be a duty to undertake a carer’s assessment in our future adult social care statute.***

***Provisional Proposal 5-2: We provisionally propose that the duty to assess a carer should apply to all carers who are providing or intend to provide care to another person, not just those providing a substantial amount of care on a regular basis.***

***Provisional Proposal 5-3: We provisionally propose that the duty to assess a carer should not be triggered by the carer making a request, but should be triggered where a carer appears to have, or will have upon commencing the caring role, needs that could be met either by the provision of carers’ services or by the provision of services to the cared-for person.***

Unpaid carers are at a significant economic and social disadvantage, and this disadvantage falls disproportionately on women (Himmelweit and Land, 2008). Carers tend to be in poorer health themselves, but are often unwilling to ask for help (Walker and Walker, 1998) and feel the need to be seen to be coping (Philips, Bernard and Chittenden, 2002). JRF research into carers who work also concluded that without more resources to support carers, their contribution may not be sustainable. Flexible working hours, the opportunity to reduce hours or take a career break without financial penalties, and good quality, affordable support for carers and care recipients would help employees to combine care and work (Mooney *et al.*, 2002).

Carers' need for support cannot be judged based on how long and frequently they provide care, as this takes no account of the nature or intensity of the care being provided. JRF therefore supports the Commission's provisional proposals 5-1, 5-2 and 5-3 so that all carers are entitled to an assessment of their own need, regardless of how many hours' care they provide. Including an automatic trigger to offer an assessment, alongside carers being able to request an assessment, may encourage take-up among those who may be unaware of their entitlement or who are unwilling to ask for help.

***Question 5-1: Should our proposed adult social care statute encourage a more unified assessment process for carers and cared-for people?***

In 1998, JRF research into the social care assessment process found that there was a tendency for practitioners to categorise people as either 'users' or 'carers'. This meant that the complex and changing patterns of caring relationships in many households were not taken into account in assessments (Davis, Ellis and Rummery, 1998). Little appears to have changed from this time, as many subsequent studies have identified the complexity of entitlement and eligibility for carers as a source of distress and frustration for both carers and those they care for.

Although caregivers are a heterogeneous group, there is a clear association between caregiving and disadvantage. In general, people providing care for 20 or more hours per week are more likely to have health problems themselves and to live in poorer areas and in households with fewer resources, and are less likely to have educational qualifications or to be in employment (Young, Grundy and Jitlal, 2006). Yet many carers miss out on benefits and services they would be entitled to because of the complexity of accessing them (Cattan and Giuntoli, 2010), as well as a resistance to asking for help and the need to seem to be coping (Philips, Bernard and Chittenden, 2002). As such, any attempt to simplify the existing assessment system and to promote access to benefits, entitlements and support is welcome. A unified assessment process for carers and service users (where appropriate) would reap significant benefits in creating a clearer and more integrated (and person-centred) approach to care and support.

**Section 21 of the National Assistance Act 1948 and Section 2(1) of the Chronically Sick and Disabled Persons Act 1970 (Part 7 of the consultation paper)**

***Provisional Proposal 7-1: We provisionally propose that section 21 of the National Assistance Act 1948 should be repealed and that the Government should ensure a proper scheme for the provision of residential accommodation to those people who might lose their entitlement.***

***Provisional Proposal 7-2: If the Government does not introduce a proper scheme for residential accommodation, we propose that section 21 should be retained but only in relation to those people who would otherwise lose their entitlement.***

JRF supports these proposals, but favours the first, as it would provide valuable clarity to a system which is both confusing for individuals and which is interpreted differently by different local authorities. Research commissioned by JRF regarding the Government's *Supporting People* programme (Fyson *et al.*, 2007) found that local authorities were applying section 21 of the National Assistance Act 1948 differently as a means of restricting funding, with some arguing that Supporting People monies should be used exclusively for individuals who did not attract a statutory duty of care (that is, were not eligible for support from either health or social services).

Supporting People officers were very aware of this distinction and sought to ensure those with statutory entitlements to residential care claimed this, but health and social care teams were not aware of the issue that some people with statutory entitlements to support from them were instead claiming non-statutory support (Fyson *et al.*, 2007). This 'cost shunting' of people with learning disabilities between statutory and non-statutory funding could lead to uncertainty and confusion for the people involved and local variability of service. A proper scheme for residential accommodation specifically reserved for those without health and care needs would end this confusion and clarify the division of responsibility between housing and health and care teams at local level.

## **Scope of adult social care services (Part 9 of the consultation paper)**

***Provisional Proposal 9-1: We provisionally propose that community care services should be defined by a short and broad list of services.***

***Question 9-1: Do you think that community care services should be undefined in our future adult social care statute?***

***Provisional Proposal 9-2: We provisionally propose that the list of community care services should be set out on the face of our future adult social care statute.***

JRF strongly supports the concept of having an open definition of social care in the statute rather than a list of prescribed services. With the advent of personal budgets and more innovative, preventative approaches to supporting people in the community, it would seem dated for service users and commissioners to have a pre-set menu of services from which to choose. Moreover, the Commission itself proposes that assessments be based on needs and outcomes rather than eligibility for specific services (provisional proposal 4-2). It would seem incongruous to have such a form of assessment, which then needed to be fitted into a list of services.

JRF research with service users and providers suggests a narrow, service-centred approach undermines the principle of person-centred support (Glynn and Beresford, 2008), and that many service users have needs which fall beyond the current limits of social care services (Turner, 2003). In successive consultations with different groups of service users, aspects of life such as personal identity and self-esteem, social and intimate relationships, and a sense of belonging to and participating in communities and wider society have all been identified as important (Godfrey *et al.*, 2004 and Bowers *et al.*, 2009).

Others have also identified the importance of meeting emotional needs – including trust and relief from loneliness (Cattan and Giuntoli, 2010). These needs and outcomes, which may well be identified during a co-produced assessment, do not have an obvious fit with the services outlined in the Commission's proposed list (the closest might be 'social activities'). By defining *any* list of services that have to meet needs and outcomes in all their diversity, it is likely the list will fall short.

JRF research with disabled parents demonstrates this point, and shows how even an open service-based definition of care could mean some service users miss out on vital services. Disabled parents require social care support and assistance in the home to help them with parenting tasks. Yet in practice local authorities are unsure whether assistance with parenting is an adult social service or whether it should fall under children's social care (Morris, 2003; Olsen and Tyers, 2004; Morris, 2004b). The broad list outlined above could still leave this particular issue unaddressed.

JRF would therefore suggest the definition of community care services are, like proposed assessments, needs and outcomes based. For example, the definition might be: *'any service delivered in the home, residential or communal setting which supports and promotes the physical or mental wellbeing and independence of those with social care needs'*. To fully align this with the proposed principle in Part 3 regarding preventative/low-level care, one could also add *'...and which may reduce or delay the need for more intensive support.'*

***Provisional Proposal 9-3: Provisionally, we do not propose that our future adult social care statute should include a central definition of a disabled person or service user.***

It is concerning that the phrase 'disabled person or service user' is being used as if these two terms are interchangeable. This concern is given weight by the Commission's proposal that: 'the provision of community care services would depend entirely upon a community care assessment of need and the eligibility criteria and not a central definition of people who can be provided with services.'

Definitions are unhelpful when they mix together concepts of impairment, support needs, eligibility criteria and the disabling barriers that people experience. JRF would suggest the Commission refers to the Office for Disability guidance on this matter – which recommends a 'social model' of disability be adopted as good practice rather than a 'medical model'. According to this model:

*Impairment* is an injury, illness, or congenital condition that causes or is likely to cause a long-term effect on appearance and/or limitation of function of the individual.

*Disability* is the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.<sup>3</sup>

***Provisional Proposal 9-4: We provisionally propose that carers' services should remain undefined in our future adult social care statute.***

JRF supports this proposal. Research shows that carers are a diverse group in terms of age, socio-economic status, relationship with those being cared for (Young *et al.*, 2006), and the type of care and support being provided (Phillips *et al.*, 2002). Carers may have to balance their caring role with a job, with education, or with caring for their own children. As such, carers will need a wide range of support to meet their specific situations – this may include information and advice, through to practical help, respite, and direct financial assistance (Himmelweit and Land, 2008).

Keeping carers' services undefined as in current statutory guidance ensures the support provided can be flexible and based on needs and situation, recognising the diversity of the caring population, the variety of the caring role, and the very different social, practical and financial contexts in which care is delivered.

***Provisional Proposal 9-6: We provisionally propose that the existing divide between health and social care service provision should be maintained in our future adult social care statute. This would mean that local authorities would be prohibited from providing residential accommodation, if this is authorised or required to be provided under the NHS Acts 2006; any non-residential services that are required to be provided under the NHS Acts 2006; and nursing care which is required to be provided by a registered nurse.***

JRF research suggests that the Commission needs to recognise the increasing overlap between these two realms, particularly for people with high-level support needs. In particular, *nursing care which is required to be provided by a registered nurse* should be recognised as a fluid concept (as the areas that should be provided by a registered nurse are not laid out in statute, but rather are identified by an assessment led by a registered nurse). Recent JRF research into pilots which up-skilled residential care staff to complete basic clinical tasks potentially challenges the assumption that some tasks need always to be carried out by a registered nurse (Wild *et al.*, 2010). Whilst this does not challenge the legal distinction between health and social care, any

principle emphasising this divide will need to consider such areas of overlap.

This overlap is also important from a care planning and quality perspective, as outlined in proposal 11-11. JRF research exploring the implications of providing nursing support in residential care homes concluded that:

... it is important for residents to receive a more comprehensive routine health assessment than one which is focused on functional “activities of daily living”, as a precursor for better care planning and intervention. This has implications both for the knowledge level required by care home staff taking on “new types of working” roles and for the level of support they may require from a nurse. (Wild *et al.*, 2008)

As such, the distinction between health and social care should be maintained in the statute, but should be described in a context where increased integration and joint working of these two realms should be standard practice and encouraged to promote more positive outcomes.

## **Delivery of services (Part 10 of the consultation paper)**

### ***Question 10-1: Should direct payments be extended to cover residential accommodation?***

JRF would strongly support a move to extend direct payments to cover residential accommodation. Excluding those in residential care from having direct control over their finances, a benefit extended to all other service users, is both unfair and inequitable in principle and may also limit the choice and control that can be exercised by care home residents. Research among older people in residential care found that a lack of financial control contributed to their sense of disempowerment:

The idea that control over one’s money equates to control over one’s life needs further exploration. There was a feeling among study participants that people with money had more control over their care. In this context, they were talking about ‘self-funders’, but the same principle should apply to individual budgets ... Discussions about money and the care market led to the conclusion that older people with high support needs are seen and

treated as commodities, not as consumers with rights, entitlements and purchasing power.  
(Bowers *et al.*, 2009)

Whilst supporting this proposal, JRF also highlights the well-documented barriers to making direct payments happen, and ingredients for success (e.g. Hasler and Stewart, 2004).

### **Joint working (Part 11 of the consultation paper)**

***Provisional Proposal 11-1: We provisionally propose that our future adult social care statute should apply to those aged 18 and above, and the Children Act 1989 (and the CSDPA 1970) should apply to those aged 17 and below.***

JRF supports the Commission's attempt to clarify the law regarding children's and adult's support services. The transition to adulthood for young disabled people is characterised by poor liaison between different agencies and professionals in children and adult social work teams, a failure to involve young people in transition planning and a failure to cover the issues of most importance to them and their families (such as maintaining friendships and having a role within their family and community). Moreover, the complex system of varied sources of assessment, funding and provision of equipment and support make it difficult for young people to get equipment and support when they need it (Morris, 2002).

***Provisional Proposal 11-2: We provisionally propose that local authorities should have a power to assess 16 and 17 year olds under our proposed adult social care statute and young people aged 16 and 17 (and their parents on their behalf) would have a right to request such an assessment.***

Given the multiple challenges faced by young people leaving care and the association of poorer outcomes with transitioning from children's care earlier (Stein, 2005), JRF disagrees with the Commission's proposal of giving local authorities the power to assess and provide adult services to young people aged 16 and 17. It is important that a disruptive and abrupt transfer to adult services, which could imply a break in relationships with professionals that may have built up over many years, (Stein, 2005) is not undertaken at such an early age as 16.



Local authorities' *power* to treat 16 and 17 year olds under adult social care provision could risk this being *imposed* on a young person in a forced move from residential care. Policy is moving in the direction of enabling children in care to remain in their placements longer, potentially to 21, so the Commission's proposal of enabling adult services to be triggered at 16 and 17 is potentially contrary to this shift in approach. It would be more effective to emphasise an enhanced duty to co-operate (described below) as a means of smoothing the transition from children's to adult's services rather than seeking to overlap adult and children's care services in this way.

***Provisional Proposal 11-10: We provisionally propose that our future adult social care statute should place a general duty on each social services authority to make arrangements to promote co-operation between the local authority and specified relevant organisations.***

***Provisional Proposal 11-11: We provisionally propose that our future adult social care statute should specify that a local authority can request certain authorities to assist in a number of circumstances, including when an assessment of a service user or carer is taking place and in providing services to a service user or a carer. In such cases, the requested authority would be under a duty to give due consideration to the request.***

JRF strongly supports the provision of a general and specific duty for social services and other bodies to cooperate in supporting people with care needs. In line with a person-centred approach, a general and specific duty to cooperate should include *all* statutory services that could support someone with support needs, reflecting the very wide range of needs and outcomes that may be identified.

JRF's *Shaping our lives* project clearly indicated that service users considered issues such as housing, transport, employment, income and benefits, and broader issues around discrimination and equality holistically (Turner, 2003), and it would be incongruous for some service areas to be better integrated with social care than others. Statutory services that could support those with social care needs would clearly include health and mental health, housing, transport, education and training, welfare to work, local-authority owned leisure services, children's services (of particular importance to disabled young people and disabled parents), and any others that may be available in particular local authorities.

A recent JRF evaluation of pilots which created a greater overlap between personal care and nursing care by up-skilling residential care workers showed that this could deliver more person-centred care and provide a home for life for their residents, rather than residents having to move to a nursing home as their needs escalated (Wild *et al.*, 2010). The then Commission for Social Care Inspection (now Care Quality Commission) was pragmatic for the purposes of the pilots and gave special permission to two pilot sites to allow nursing care to be delivered in homes registered as residential (usually this would be forbidden). This is one example of how the barriers between health and social care stand in the way of person-centred support and why a better integration between the two is urgently needed (Wild *et al.*, 2010).

It may be that a duty to cooperate between 'specific relevant organisations' (The Commission mentions education, health and housing) is too limited an approach. Given the needs and outcomes based principle of care proposed in Part 3, and JRF's argument for having an open definition of community care services based on needs and outcomes (see provisional proposal 9-2), it would seem incompatible to have a pre-determined list of services with whom social services would have a duty to cooperate in order to meet service users' needs. There are groups of service users that require a very wide range of agencies working in a seamless way.

For example, JRF's research with disabled parents has found that although assistance with parenting tasks should be available within the current community care framework, disabled people are often told that they can only access support through children and families services. Parents often find they can only get a response from services when things reach a crisis, at which point they can be at risk of losing their children into care (Morris, 2003; Morris, 2004b).

Similarly, people with both physical impairments and mental health needs have complained of poor integration between these two very separate service areas: one interviewee told researchers, 'I have to go to one town for my mind, another for my body' (Morris, 2004a). This fragmentation also took the form of a failure of mental health services to take account of needs relating to physical impairment, and a corresponding failure of physical disability services to take account of mental health experiences and support needs.

There was also a lack of communication between the two types of services (Morris, 2004a). Both of these groups – disabled parents and those with mental and physical support needs – require very specific types of joint working and would not necessarily have their needs met if the Commission’s list of ‘specific relevant organisations’ (and the Commission only mentions education, health and housing) did not recognise these particular circumstances. There are likely to be many other similar examples and it is highly unlikely that a list of specific relevant organisations would manage to cover all circumstances.

### **Strategic planning (Part 13 of the consultation paper)**

***Provisional Proposal 13-3: We provisionally propose that our future adult social care statute should place a duty on a local social services authority to provide information about services available in the local area.***

JRF welcomes a duty for local authorities to provide information about the availability of services – a lack of information to make decisions has been identified as a barrier to choice by those with learning disabilities (Hart *et al.*, 2007). This is also a significant problem for older people in managing their resources effectively, who report relying on word of mouth due to a lack of official sources of basic service information (Hill *et al.*, 2009).

However, JRF believes that the duty should also include a duty to provide advice and advocacy. By 2011 all councils in England will be expected to have made significant progress towards putting in place ‘universal, joined-up information and advice for all individuals and carers, including those who self-assess and fund.’ (Horton, 2009). As such, local authorities will have to meet the proposed duty, *and exceed it*, by also providing advice alongside information. In this context a duty to provide information alone seems superfluous.

Several JRF studies have pointed to the fact that information in itself is not enough. Older people clearly state that they often need more than ‘signposting’: they also need guidance and support (Horton, 2009). Whilst the term ‘advocacy’ is not well understood by service users, the concept – having someone to speak on your behalf and take more hands-on action to sort things out above providing advice – is valued.

People do not generally find distinctions between information, advice and advocacy meaningful and require a seamless spectrum of support encompassing all three elements (Quinn *et al.*, 2003; Margiotta *et al.*, 2003). Advocacy in particular – including peer advocacy and collective advocacy through user-led organisations – is essential if ‘information and advice’ and ‘personalised care and support’ are to be effective and meaningful to people using services (Godfrey *et al.*, 2004; Horton, 2009). By including a duty to provide information, advice and advocacy, the Commission would be taking a significant step in helping to meet this need, but would also be supporting the principle of choice and control by enabling more service users to have their voices heard through an advocate. This would be particularly important for those service users who are least able to express their preferences and needs for themselves.

## Conclusion

As our response demonstrates, JRF is very supportive of the general aims and focus of the Law Commission Consultation on Adult Social Care legislation. A single statute which clarifies social care law for service users, their families and practitioners is much needed. Our response has highlighted a number of issues which we feel may have been overlooked and which, based on our research and practice, we believe deserve greater prominence:

- 1) User voice – giving more explicit reference to active involvement of service users (individually and collectively) in setting the agenda for social care and support.
- 2) Human and civil rights as a founding principle on which the new statute is based; other principles are a means to this end.
- 3) A stronger focus on outcomes and needs, rather than services; there are several places in the document where a service-based approach remains, and is at odds with key principles.
- 4) Recognition that information alone is not enough; advice and advocacy are essential.

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## Notes

1. See <http://www.jrf.org.uk/sites/files/jrf/older-people-vision-for-care-full.pdf> and <http://www.jrf.org.uk/sites/files/jrf/user-involvement-service-commissioning-summary.pdf>
2. See [http://www.southamptoncil.co.uk/basic\\_needs.htm](http://www.southamptoncil.co.uk/basic_needs.htm)
3. See <http://www.officefordisability.gov.uk/resources/models-of-disability.php>

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