

# Disability Rights UK



## Draft Care and Support Bill [Department of Health]

Consultation response  
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### About Disability Rights UK

Disability Rights UK was formed through a merger of Disability Alliance, Radar and the National Centre for Independent Living on 1 January 2012. We aim to be the largest national pan-disability organisation led by disabled people. Our vision is of a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

Disability Rights UK's objectives are to:

- mobilise disabled people's leadership and control
- achieve independent living in practice
- break the link between disability and poverty
- put disability equality and human rights into practice across society.

### About this response

Our response has been shaped by the combined expertise of our predecessor organisations, the evidence from our helpline and members, including people who responded to our survey on the draft Care and Support Bill. We are responding to Part 1 of the Bill only.

## Key points

- Disability Rights UK welcomes the draft Care and Support Bill ('the Bill') which should end some of the complexity of the current multiple care legislation. The simplification and harmonisation should clarify councils' duties and disabled people's entitlements to support. However we have concerns which we have highlighted in this response.
- There is a real crisis in care. Resolving the crisis is as much a matter of funding as of law reform. Extra funding is desperately needed to raise the standards of social care and support and give disabled people true control over their support. Dilnot and others have suggested that an additional £2 billion is required just to meet existing demand.<sup>1</sup> We urge the Government to accept the recommendations, make resources available and put in place a sustainable system as a matter of priority.
- We strongly welcome the general responsibilities which form the backdrop to the other provisions in the Bill. For the effective promotion of these duties, it is important that their implementation is monitored and that local authorities are held accountable (not just when disputes arise). This needs to be at local as well as national level.
- We welcome the new rights for carers as currently many go without support and this is to the detriment of the disabled person and their relationship with each other. However we are concerned that the approach taken in the Bill shifts the emphasis from a disabled person's independence to a 'partnership' of the disabled person and the carer. Safeguards are needed to ensure that the disabled person has full autonomy and that their partners, relatives and friends are not inappropriately involved in their care and support.
- Disabled people must be given the support that they need to have choice and control both in the assessment and the care and support planning. The proposed legislation needs to be strengthened on these points.
- Disability Rights UK wants the new law to introduce a national charging system that is fair and clear, and reflects the true costs of disability-related expenditure. Disabled people and their families should be able to enjoy adequate standards of living as well as realise their aspirations.

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<sup>1</sup> See [www.dilnotcommission.dh.gov.uk](http://www.dilnotcommission.dh.gov.uk)

- We welcome the right to a personal budget and the right to request a direct payment. Whilst we understand that the Government wants people to have flexibility; the way the law is worded, there is a risk that it will be harder for people to get direct payments whilst direct payment users will lose discretion in the way they use their budget to meet needs.
- Disability Rights UK believes that it is a fundamental right for disabled people to be able to move to another area. We warmly welcome the 'continuity of care' provisions but they do not go far enough to give people the confidence that they will continue to have the care and support that they need. We have included suggestions to achieve that intention.
- Disabled people report that they have to wait a long time before they get the care and support they need. Even if they have made a complaint and the local authority has agreed to provide a certain care package, then it may still take a long time for this to be put in place. The draft Bill lacks provision for a reasonable timeframe and an effective reporting and complaints system. At the very minimum the Bill needs to link to the Health and Social Care (Community Health and Standards) Act 2003.<sup>2</sup>
- When the bill becomes law, the government needs to actively promote the new legislation so that local people know what their rights are and they can hold their local government to account. We would like to build on our strategic partnership to help raise awareness, explain what the changes mean and to feed back any issues to the Department of Health.
- Local authority staff will need to be supported through the implementation of the new legislation. We are concerned 'efficiency savings' made by local authorities have reduced their ability to implement the new law and to train the staff. We call on the government to make resources available to support the effective reform of care and support.

## **Clause-by-clause response**

### **General responsibilities of local authorities**

#### ***Promoting individual well-being (Clause 1)***

At the heart of the Bill is the duty on local authorities to promote the adult's well-being. We strongly welcome this new duty which

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<sup>2</sup> <http://www.legislation.gov.uk/ukpga/2003/43/contents>

sets the parameters for the other duties and powers of local authorities. The well-being duty should usher in an approach to social care as a key enabler for disabled people to realise their full potential and to support their life choices (rather than the provision of social care as an end in itself).

We welcome the set of outcomes, described in subsection (2), and the matters that the local authority must have regard to (subsection 3). They form a holistic approach to an individual's wellbeing.

However it misses a vital area, namely the enjoyment of human rights and equality. Respondents to our survey asked to include dignity, independence, self-determination. These are all matters covered by (international) human rights law. The UN Convention on the Rights of Persons with Disabilities (the 'Convention') requires the UK Government to ensure that local authorities are doing what is necessary to implement the Convention

For these reasons we recommend that the list in subsection (2) is expanded with "the adult's full enjoyment of their human rights" and that subsection (3) also requires local authorities to have regard to the 1998 Human Rights Act and the 2010 Equality Act.

We would welcome clarification of the intention behind subsection (3)(e) - the importance of achieving a balance between the adult's well-being and that of any others who are involved in caring. In our view this carries a risk that local authorities will accord more weight to carers' views than they should. However if we should read this as "need to support the individual so that their relationship is not undermined" i.e. friends and relatives should not be presumed to be a carer or the disabled person should be able to say that they do not want their friend or relative to care for them, then we would welcome this; and we would like to work with the Department of Health on wording that better reflects that intention.

There will need to be strong guidance on the well-being duty. For example, 'relationships' need to include parental and caring responsibilities that a disabled person may have.

Many survey respondents were ambivalent about the 'contribution to society' as they were concerned that this would place a reciprocal duty on the individual to make a financial contribution. Disability Rights UK believes that 'contribution' is to be read as 'social participation' or 'contribution to the community' such as volunteering, carrying out jury service, holding an elected post. Guidance needs to clarify this.

Other issues that need to be covered in the guidance are:

- it applies to all individuals regardless of where they live (including prisons)
- choice includes choice of where a person lives (this links in with the provision of services as well as portability)
- physical health includes staying warm
- economic well-being includes managing own finances
- transport and communication are vital means to achieve the outcomes listed in subsection (2).

### ***Providing information and advice (Clause 2)***

Disability Rights UK strongly welcomes the duty to provide information and advice. The White Paper rightly recognises their importance in accessing care and support and in supporting the exercise of choice and control.

However we urge the Government to include advocacy as a distinct service. Advocacy is an important means to ensure that disabled people who need it can fully participate in the process. We are concerned by the omission of independent advocacy and we urge the Government to expand the duty in Clause 2 to cover independent advocacy. Failure to do this will result in a postcode lottery across the country where some areas will offer a strong advocacy service but other areas not.

It is vital that the duty to provide information, advice and advocacy is a pro-active duty – i.e. the local authority must actively set out to ensure that information and advice reaches people in the community. That is because many people are not aware of their rights or understand how the system works. In reaching out, the local authority will need to address the range of barriers that stand in the way of accessing information:

- language (e.g. people who do not have English as their first language)
- cultural (e.g. people seek help within their family or community rather than contacting a local authority)
- attitudinal (e.g. people do not believe they need support or are reluctant to accept that they need support, for example if they have the early stages of dementia)
- format (e.g. information is provided online only or in another format that is not accessible)

For this reason we recommend that Clause 2(1) be amended so that the duty on local authorities is to “establish, maintain and facilitate access to advice, information and advocacy”.

We believe it is important to qualify in subsection (1) that information and advice must be impartial and that advice and advocacy are provided independently.

Many people find it difficult to understand how local authorities charge for services and what options they have to pay for support. This is disempowering and it means that people may end up paying more than they should. Furthermore, charging varies across the country and the lack of information about charging arrangements forms a real barrier to portability. For these reasons we call on the Government to include in Clause (2)(2):

- any relevant charging arrangements for care and support in the local authority’s area
- independent financial advice on the options for payment for care and support.

People with a care package who move into the new area often need information not just about care and support but also about housing (provision as well as housing adaptations), local benefits, health services and transport. This needs to be included in the information duty.

### ***Promoting diversity and quality in provision of services (Clause 3)***

Disability Rights UK strongly welcomes the new duty to promote diversity and quality in the provision of services. Disabled people often have to fit their lives around care provision rather than the other way around.

As part of the Caring for our Future engagement, the Department of Health enabled Radar, a founding member of Disability Rights UK, to run workshops with disabled people about shaping local care services. Disabled people highlighted the lack of a strategic approach to the local social care market – evidenced through a rigid commissioning strategy and a lack of services that meet disabled people’s needs. In particular, it was reported that many services are designed as a ‘one size fits all’ which means that services are often not appropriate in terms of age, culture or gender.

Too often disabled people's choice and control over their life depend on the range of services available locally. We regard this as an infringement of their right to independent living (Article 19 UN Convention). Making the market far more responsive to local people's needs would be a significant step forwards.

We welcome the recognition in the White Paper that users have a central role to play in shaping responsive care services. However this is not clear from the duty in Clause 3.

We recommend that the Government include a duty to have regard to the importance of the views of service users (in subsection 2). Without it there is a real risk that the market becomes monopolised by 'preferred providers' in the private sector. A caller to our helpline complained that they had been excluded from choosing a housing provider for her daughter. Previously they had been involved; however the local authority now quoted 'EC regulations' as a reason for excluding them from the selection. This is nonsense and it should be made clear in guidance that users can, and should, be involved in the commissioning of services.

Only half of disabled people are in work. More effective support would mean that disabled people find it easier to search for a job and access employment or education opportunities as they arise. Following the second reading of the Social Care (Local Sufficiency) and Identification of Carers Bill, we urge the Government to include the need for the market to meeting an adult's needs for services to enable them to participate in work, education or training – for example in subsection 2.

When people have low-incidence needs and require specialist support, it can be difficult for the market to respond effectively. Often they may have to move to another area to access the services they need. We welcome subsection (4) that enables local authorities to work together, and we would like statutory guidance to encourage them to use this as a way to bring services closer to people who need them. However, we urge the Government to go further and take a role in planning services for meeting low-incidence needs or for providing highly specialised support (as the NHS Commissioning Board does for health services, for example).

Because this is a new duty, again it will be important to create a bank of guidance for local authorities which covers areas like joint commissioning with users, pooling resources, flexible commissioning (for example, if a disabled person moves into the area and they need a specific service that is not readily available) and encouraging supplier diversity by supporting local user-led

organisations and stimulating disabled-led social enterprises, for example.

### ***Co-operating duties (Clauses 4 and 5)***

We welcome the co-operating duties outlined in Clauses 4 and 5. Disabled people often need support from different authorities and in order to join up the support and streamline it, these authorities must work together.

We understand that the powers to enable joint working are contained elsewhere (for example, the right to control powers are contained in Part 2 of the 2009 Welfare Reform Act and the powers for pooling health and social care budget are contained in the NHS Act 2006).

However, in relation to housing needs, disabled people need more support which are currently not addressed by the law. From our network events early 2012 we found that disabled people are having to live with their parents because of the lack of social housing. For example, a visually impaired man in his 40s who doesn't have a job, can't find anywhere suitable to live and private rents are too high. We welcome the extra funding for specialist housing but the vast majority of people will live in 'ordinary' housing. We need more regulation over new builds to avoid future expenses of adaptations – at the very minimum the Lifetime Homes and Neighbourhood standards should be adapted. Many disabled people live in the private rented sector and need more protection. The 2010 Equality Act contains a provision that makes it unlawful for landlords and management committees to unreasonably refuse consent for adaptations to common parts (e.g. shared hallways) yet the Government has not enacted this. We urge the Department of Health to raise these matters with their colleagues in the Department for Communities and Local Government and the Government Equalities Office as a matter of urgency.

We believe that there are a few omissions from the duties which need to be addressed:

- the range of public authorities. Conspicuously absent are the providers of further and higher education (including adult and community education). Also absent are benefits authorities, for example it may be necessary to work with Jobcentre Plus. We would welcome confirmation that GPs and GP consortia are covered by the cooperating duties (as an 'NHS body').



- the need for consent of the adult to share information with other authorities unless it is necessary to operate without that consent.
- the enforcement of the co-operating duties in specific cases. Our members have told us that some local authorities tend to just give up if they do not get the co-operation they need.

### *Integration of NHS and social care (Clause 6)*

We welcome the duty to promote integration of care and support with health services. Many disabled people have social care as well as health needs. They would benefit from further integration of health and social care provision. For a successful integration it is necessary to develop choice and control in the NHS further, particularly in relation to personal health budgets. We welcome the commitment in the White Paper to do this.

In relation to NHS continuing care assessments we urge local and NHS authorities to put in place a process to ensure that individuals do not have to go through intensive assessments twice and have to repeat information more than once.

### *Preventing needs for care and support (Clause 7)*

Disability Rights UK welcomes the duty to develop services to prevent needs for care and support. Many of our members already have needs for care and support but, if these are not being met (effectively), then they are at risk of developing further needs or their needs may become more acute. We are not clear whether the prevention duty covers these people – we think it should.

We also believe it is vital that guidance makes it clear that prevention should not restrict the ability of local authorities to meet eligible care and support needs. A particular concern raised by our survey respondents was whether the new prevention duties mean that there will be even less money available for meeting existing care and support needs.

Subsection 3 gives local authorities the power to charge for prevention. Disability Rights UK opposes any charge that would stop people from accessing these services. It is highly likely that people who need preventative services the most are the ones who would be put off by charges. Furthermore we believe that all powers to charge must be contained in Clause 14.

For these reasons we urge the Government to delete subsections 3 and 4.

Guidance will need to clarify what is covered by this duty.

***Meeting needs for care etc. (Clause 8)***

Clause 8 provides examples of how needs might be met.

It appears to use that ‘advocacy’ is in the wrong place and should be grouped with information and advice – these are ‘enabling services’ which ensure that an individual can exercise choice and control, make informed decisions and hold a local authority to account.

We appreciate that this list is not exhaustive, but we think it may be helpful to add ‘equipment’ (in so far it is not covered by ‘goods and facilities’) and ‘transport’. Provision of transport is particularly important in areas where there is limited availability of public transport and the person is not able to drive.

***Assessing needs (clauses 9-12)***

Assessments are the gateway to accessing care and support – often for people with highly individualised needs and outcomes.

It is therefore vital to get the duties right. In particular, the local authority must ensure that the assessment process is done *with* the disabled person. They must also ensure that the adult is able to participate in the process. The benefits are that the local authority would be able to meet needs more effectively (thus spend public money where it makes a positive difference), that disabled people are confident that they are listened to (thus less stress and anxiety) and that there is less risk of making assumptions (as the person is able to explain what needs they have).

Clause 1 is of critical importance with regards to the needs assessment but we urge the Government to reinforce its importance by going beyond the requirement to ‘consult’ the adult and to demand their active engagement (subsection 5).

We believe that it is right to consult the carer, as they often see things that others do not. However we are concerned that the duty is not qualified. Disability Rights UK has heard how difficult it is for a young disabled person to move towards a life away from parents (who may be overprotective), about disabled people’s frustrations with councils giving more weight to the views of the carer (especially if the disabled person has a communication impairment and they do not have an independent advocate) or they should be content with informal care if that’s what the carer wants.

In order to discourage this practice as well as to promote transparency, we strongly recommend a duty on local authorities to

set out in writing how they have listened to the adult and the carer and resolved any conflicting views or interests.

We welcome the focus on outcomes, but there will need to be strong guidance on this. In particular, these outcomes must not become a 'performance indicator' and they must not be shaped by low expectations, for example.

Guidance must also include the importance to provide disabled people with the support they need to be a 'good parent' for example. Unfortunately too many disabled parents are having their child(ren) removed because they are deemed unable to care for the children – without considering what support might help them. This is a breach of their human right to a family life. One survey respondent told us of a young woman with learning disabilities who had just had a baby and needed extra support. However she did not request an assessment because the family was worried that her child would be removed.

#### *Carer's assessment*

We welcome the clear entitlement to a carer's assessment. However we are surprised that whilst a carer must be consulted in relation to an adult's assessment; there is no requirement to consult the adult in carrying out the carer's assessment. We think that this is an anomaly that undermines Clause 1 – and this must be redressed by including the adult in the consultation duty (Clause 10 (6)).

Some people use direct payments to employ a relative or partner as a personal assistant. We are concerned that the draft Bill excludes them from carers' rights to assessment and services, even though this is not the intention stated in Detailed Note 21. Clause 10(7) should make it clear that a carer who is paid through direct payment but whose relationship is primarily characterised as being domestic, family or personal should not be excluded from the definition of a carer.

#### *Refusal of assessment*

The Bill says that a local authority does not have to carry out an assessment if the adult refuses it – except if the adult lacks capacity or if the adult is experiencing, or is at risk of, abuse or neglect. We believe that this does not take account of the reasons why a person may refuse an assessment; for example, if they feel it diminishes their dignity; or if the assessment is not carried out by an appropriate professional (e.g. someone with mental health training). Many of our members report that they are worried about

an assessment for fear of losing their care and support or because of their experiences with the benefits assessments which may have left them traumatised. Some people also prefer to be assessed by an independent body rather than social services.

We would not want a local authority to discharge of their duty if they could address the reasons for the refusal through, for example, providing information or ensuring that the assessment is done in an accessible way. We would welcome a discussion with the Department of Health as to how the Bill can address this.

We think that there needs to be an additional subsection requiring the local authority to follow up with an offer of an assessment within a reasonable time (if the needs are still apparent).

#### *Further provision*

We broadly welcome the areas that are suggested for regulations but we would like to see these tightened up –

- the assessment must be carried out in an appropriate and proportionate manner
- the adult must receive a copy of the assessment in a format that they understand (and this may mean a face-to-face explanation)
- information about the adult and the carer can be shared only with their knowledge

We welcome the powers to combine a needs assessment of adult and carer and to carry out a single assessment – but we would welcome clarification why in the first case consent is required but in the case of a single assessment no such requirement exists.

In the case of a combined assessment, there needs to be an additional regulation to ensure that this results in two separate reports with clearly identifiable needs for each person. This is particularly vital in relation to charging arrangements.

#### ***Eligibility criteria (Clause 13)***

The eligibility framework determines whether a local authority will meet the assessed needs. We recommend that this is made explicit by stating in Clause 13 (1) that where a person's needs are found to meet the local authority's eligibility criteria, the local authority is responsible for ensuring that those needs are met.

The current eligibility framework is not working well.

- Over four in five local authorities only meet needs if they have been assessed as falling in the 'critical' or 'substantial' band, with some going even further and only meeting those needs

that have been identified as ‘critical’. We welcome the message in the White Paper that local authorities should set their eligibility threshold at ‘substantial’, not higher.

- The interpretation of what ‘band’ applies to needs varies across the country. This is not just unfair but it is also problematic for people who move from one area to another and find that their needs are not longer eligible for care and support because they’re now deemed to be ‘moderate’ not ‘substantial’, for example.
- Local authorities tend to attach more weight to personal care needs than to communication, social interaction and mental well-being.

The Bill has an enabling power to set a minimum eligibility threshold above which local authorities must meet eligible needs. While we welcome this suggestion we do have reservations of how this might work out in practice – i.e. local authorities will not meet needs beyond the threshold even if their resources allow it. We would therefore welcome some kind of provision that encourages local authorities to expand the scope of eligibility.

We would welcome an opportunity to get involved with developing and testing a new model - as a pan-disability, disabled-led organisation we believe that we are ideally placed to contribute to this work.

### ***Imposing charges and assessing financial resources (Clauses 14 and 15)***

Disabled people are far more likely to be living in poverty – about a third of all disabled adults of working age live in low-income households.<sup>3</sup> Charging acts as a barrier to accessing care and support, with increasing numbers of people withdrawing from essential support.<sup>4</sup>

Disability Rights UK wants the new law to introduce a national charging system that is fair and clear, and reflects the true costs of disability-related expenditure. Disabled people and their families should be able to enjoy adequate standards of living as well as realise their aspirations.

However, there is a lack of transparency about how local authorities charge for care and support. This makes it very difficult

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<sup>3</sup> Family Resources Survey /DWP (2010) Households Below Average Income

<sup>4</sup> See, for example, Coalition on Charging [June 2008] Charging into poverty. Charging for care services at home and the national debate on adult care reform in England;

for individuals to challenge their authorities if they believe that they have been charged too much. It also poses a problem for people who wish to move from one area to another – as they do not know how charges will affect their living standards. This uncertainty is exacerbated by the significant differences in charges across the country.<sup>5</sup>

The Bill can do more to improve transparency:

- all powers should be contained in Clause 14
- all services that are currently provided free of charge by law must continue to be provided free. This includes community equipment up to £1,000<sup>6</sup>, intermediate care<sup>7</sup> and services provided under s117 of the 1983 Mental Health Act.
- any costs involved in administration and carrying out essential functions (assessment, care and support planning) should be exempt.

Currently, Fairer Charging guidance specifies that local authorities need to assess disability-related expenses (DRE). However our members report many problems with the calculations (or they may not even be aware that they are entitled to DRE). It is vital that the information duty in Clause 2 covers disability-related expenses and how these are calculated. Regulations must also require full and proper consideration of essential disability-related expenses.

In relation to the financial assessment, we would support:

- the threshold for charging to be increased to at least twice income support
- a 65 per cent taper on charges as recommended by the Dilnot report.

Clause 15 (3) relating to assessment of financial resources and carers needs is confusing. It needs to make clear that where a service is provided to the adult needing care then that adult will be charged, not the carer – even if it is a ‘carers service’ specified in the carer’s support plan (for example, respite care). This would also cover the situation that a disabled carer needs extra support to help them care for the other person.

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<sup>5</sup> Which? 2011 survey, available at <http://www.which.co.uk/news/2011/01/home-care-charges-lottery-revealed-by-which-242460/>

<sup>6</sup> S 15 Community Care (Delayed Discharges etc) Act 2003 and (Qualifying Services) (England) Regulations 2003 SI No 1196

<sup>7</sup> S 15 Community Care (Delayed Discharges etc) Act 2003 and (Qualifying Services) (England) Regulations 2003 SI No 1196

We welcome the disregard of earnings for people in residential care; this is in line with the recommendation by the Joint Committee on Human Rights.<sup>8</sup> However we would welcome clarification on how residential care will be treated in terms of charging. This will at the very minimum need to be dealt with in regulations.

## **What happens after the assessments?**

### ***Care and support planning (Clauses 23, 24 and 26)***

We welcome the duty to prepare a care and support plan. This is a vital tool in transparency and accountability and it should make clear what responsibilities local authorities and individuals have.

As with the assessment, it is crucial that the adult is fully engaged with the planning. In this context we would welcome clarification how to read Clause 23 (1)(c) (the local authority must help the adult with deciding how to have the needs met) with Clause 24 (3) (the local authority must consult the adult). We would welcome an explanation why, in the case of a support plan, the adult only has to be consulted if the carer asks the authority to do so (Clause 24(4)(b)).

We welcome the duty to give a written record (Clause 23(2)) or a copy of the plan (Clause 24(8) and (9)), but this duty must go further. It is very important that disabled people have a clear understanding of the plan and often that means additional support, for example, a face-to-face meeting.<sup>9</sup>

### ***Review of care and support plan or of support plan (Clause 26)***

We welcome the new provision in relation to reviewing the care and support plan. This would establish an ongoing relationship between individuals and the local authority. However it is important to ensure that this does not become a bureaucratic process and leads to unnecessary assessments and interventions.

We recommend that an additional subsection is inserted to provide the adult with a right to request a review if they believe the care and support plan is not working for them, for example if there is a

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<sup>8</sup> Para 184, Joint Committee on Human Rights [March 2012] Implementation of the Right of Disabled People to Independent Living, 23rd report of session 2011-12, HL 257/HC 1074, available at <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/independent-living-report/>

<sup>9</sup> Notes available here: <http://www.radar.org.uk/campaigners-and-policy-makers/all-party-parliamentary-group/past-events/> - full transcript available from secretariat on request.

breakdown in the relationship with the carer or because their circumstances have changed (e.g. they go from a part-time job to a full-time job).

Disability Rights UK is concerned to hear stories that support has been cut from one day to another. We strongly recommend that an additional subsection is added to Clause 26 that states that a local authority cannot reduce or withdraw services or payments without consultation with the adult. Regulations or guidance should then specify that the local authority should support the disabled person to find alternative support.

### ***Personal budget (Clause 25)***

We welcome the requirement to specify in a personal budget how much the council pays and how much the individual through charges (subsection 1). However, we want to see this strengthened with a requirement to set out how the council has calculated the costs.

Currently disabled people find it difficult to challenge a council's decision in relation to a personal budget or direct payments because it is not clear how the local authority has calculated the costs; for example how they have considered local rates for services; employer's contributions (as direct payments user); support services (for example managing payroll, employment-related training). Having the transparency would facilitate collaborative care planning and empower the disabled person to make decisions.

We believe it is helpful to include other funding streams in the personal budget (subsection (2)). However we recommend that the scope is extended to include education (disabled student's allowance) and employment (Access to Work, Work Choice). Employment-related funding is also included in the right to control pilots.

Many disabled people want full choice and control but prefer not to receive direct payments as it entails employer's obligations. Personal budgets need to be available in a way that they can exercise the same level of choice and control.

### ***Direct payments (Clauses 28-30, and 24)***

*Who can receive direct payments?*

Disability Rights UK supports the intention that everyone eligible for social care should be offered direct payments, unless there is a strong reason why this would not be suitable.



However the Bill threatens to restrict access to direct payments and to reduce the flexibility that direct payment users currently enjoy.

Currently local authorities must provide direct payments if requested (unless exempted by law), but the Bill changes this to a discretionary duty. Of particular concern are conditions (3)(b) and (4).

Condition (3)(b) enables a local authority to deny direct payments on the grounds that there is no help available for a disabled person to manage their direct payments. We would strongly argue that there needs to be a clear duty on a local authority to ensure that direct payments users can access help to manage their direct payments and exercise their obligations. We urge the Government to amend condition (3) to read “with appropriate help and support”.

Condition 4 duplicates the third condition and this creates confusion as to what it adds to what is already covered by condition 3. In particular it implies a low threshold for local authorities to refuse making direct payments. We urge the deletion of subsection 28 (7).

#### *How can direct payments be spent?*

Clause 24(2)(b) specifies that the care and support plan must set out how the needs will be met through direct payments, while Clause 30 (3) sets the condition that direct payments can only be used to pay for arrangements specified in the care and support plan. This is overly prescriptive and in conflict with Clause 1. We suggest that Clause 24(2)(b) is amended to replace ‘how it is those needs *could* be met’ rather than ‘will be met’ – and to remove from Clause 30 (3) the words ‘arrangements under which’. This would ensure an outcome-focused approach rather than a process-approach which is to the detriment of adults and local authorities.

Through our helpline we have taken calls from people who have had their direct payments cut and this has left them with practical problems. This is because they may still have employer obligations (e.g. they have a duty to continue payment until the end of the notice period). But we also believe it is in breach of the public sector equality duty as these decisions should be taken with regard to the impact on disabled person’s equality of opportunities.

It is vital that the local authority provides information and independent advice and advocacy to support people with managing their direct payments. For example, we are concerned that many people use self-employed personal assistants rather

than becoming their employer. This is something we strongly advise against as the HM Revenue and Customs will still treat them as employers and thus be liable for tax and NI contributions. In line with this we urge that a subsection is added to Clause 24 (2) is expanded with “what support the adult will be provided with to administer any direct payments” and Clause 30(2) to state that regulations should specify that direct payments must include an element sufficient to cover the administration costs and managing support.

Guidance should then provide that funding could be allocated for the service user to get training about employment law.

### *Direct payments for carers*

Currently carers can receive direct payments if the local authority is satisfied that this is necessary.<sup>10</sup> This is particularly helpful for families of Asian/Arab background and other minority ethnic backgrounds who are more likely to opt for the option of family member being the carer rather than employing someone else (outsider) especially in terms of personal care provision (as this is too private) and rituals (related to religion and culture). Hence spouses or parents or children will do this caring role. These families are hardly funded by the local authorities. Direct payments will help ensure that they are not driven into poverty. This position must be maintained with clear guidance when circumstances may arise that require payment to carers.

In the case that a carer gets direct payment, they must still be eligible for carer’s assessment – and we would like to see this made explicit in guidance related to Clause 10(8). For example, some disabled people who need 24/7 care are not given the funding they need for a full package, which means that family members need to cover the rest of the care needed especially night care for free. The burden on them can be intense and direct payments will only go part of the way to alleviating the burden.

### **Establishing where a person lives, etc.**

Many disabled and older people can’t consider moving to another area because they can’t be sure that they will get equivalent levels of care and support in the new area. Disability Rights UK considers

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<sup>10</sup> Community Care, Services for Carers and Children’s Service (England) Regulations 2003 SI No 762 and Guidance on direct payments for community care, services for carers and children’s services: England 2009, available at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_104840](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_104840)

this to be a significant breach of basic human rights, depriving people of choice and control over their lives, denying them job and education opportunities or the chance to live closer to family or friends.

We were therefore very pleased to see provisions to ensure continuity of care for people who move from one area to another. However we have a number of outstanding concerns.

Our members and survey respondents have told us that the main barriers to moving to another area are:

- lack of information about the provision in the new area
- interruption of care and support while the new authority puts in place a new package (or not)
- uncertainty about the new care and support package
- disputes between local authorities about ordinary residence

The impact is such that people miss out on education or employment opportunities, suffer extreme levels of anxiety and stress or simply do not move.

However some people have reported positive experiences which show that it should be perfectly possible for local authorities to take the necessary steps to enable a seamless move. There is no need for excessive bureaucracy and uncertainty.

The trigger to the continuity of care duties is when the adult (or someone on their behalf) notifies the 'receiving authority' of their intention to move, and the receiving authority is satisfied that the intention is genuine.

Guidance under this clause and Clause 2 must require local authorities to set out how people can notify them, including a named contact.

As a general principle it should be the adult who decides that they are moving from one area to another. This is particularly relevant if an adult already lives in out-of-area accommodation and they wish to move to another type of accommodation, or they move to another area for a limited time, or they are students who live in one place during term-time and in another place during holiday periods.

Subsection (2) covers the situation that an adult lives in out-of-area accommodation and they move out of that accommodation but remain in the same area – in that case the continuity of care provisions will apply. However we would welcome confirmation that it does not cover the situation that the person moves from one type

of accommodation to another (but stays in the same area). In that case the adult will remain ordinarily resident in the area of the placing authority (unless the adult triggers the portability duties through subsection 1).

We recognise that authorities that provide specialist services in their areas may be concerned about their ability to fund the care and support for ‘newcomers’ (i.e. people who are already in their area but who are funded by another authority; and who, as a consequence of portability, now become ordinarily resident in their area). It could also be a disincentive for local authorities to encourage or support the development of new specialist services in their area. It is partly for this reason that we have been calling on successive governments to create a national funding system. However a national commissioning strategy, together with the market shaping duty in Clause 3 and more direct payments, might provide a solution to limit the risk of disproportionate costs for local authorities that provide specialist services.

#### *Information*

We welcome Clauses 2 and 31(3) which should help a disabled person who is moving, or wants to, access the information they need. Clause 31(3) places a duty on the receiving authority to provide information as it considers appropriate. It is imperative that regulations or guidance require the receiving authority to report on progress they are making (or not). That way, the adult will be able to hold the sending and receiving authorities to account if they perceive that the authorities are not progressing fast enough or neglecting to take steps needed to facilitate a seamless move to the new area.

Furthermore, in order to facilitate an adult’s move they will often need information, for example, about local services, housing or housing adaptations, benefits. The local authority needs to provide this information too.

#### *Continuity of care and support*

We believe that the new legislation will encourage the ‘receiving authority’ to carry out a new assessment as soon as possible; and until they have put in place a new care and support package, they will be required to meet the assessed needs. A minimum eligibility threshold will go some way towards addressing the postcode lottery across the country if this is accompanied by a stronger framework. However we are concerned that the Bill does not do

enough to address the major concern that disabled people have which is that they will not get equivalent care and support.

At the very minimum the Bill needs to require the receiving authority to have regard to the care and support plan of the previous authority until they have put in place a new package. This would mean that they have to meet assessed needs as well as take account of the outcomes and how the needs used to be met.

Furthermore the requirement to give a written explanation of the differences in assessed needs is so important that it must be placed on the face of the Bill (with regulations setting out the circumstances when this duty may arise); and the duty must be extended to cover (a) differences in how these needs and outcomes are met and (b) reasons for the differences.

Guidance needs to remind local authorities that assessments should be proportionate as provided by regulations under Clause 12 (1)(b) – to cover both the situation that a person’s needs do not change very much as well as the opposite situation that their needs or circumstances have changed considerably. We would also welcome recognition that adults who have moved may temporarily need extra support to help them settle in, or an opportunity to ‘try’ different services.

#### *Disputes about portability*

We welcome the approach taken in the Bill to resolve disputes. We would welcome confirmation that the receiving authority will continue to fund care and support (as required by Clause 31 (6) if the dispute arises mainly between the adult and the receiving authority (rather than between the two authorities) with reimbursement by the sending authority if it is found that the adult has not changed their ordinary residence or is no longer eligible for care and support. This would avoid the adult incurring high debts because of the postcode lottery across the country.

#### *Portability and other areas*

We regret that the draft Bill does not address portability of NHS continuing care. There is no equivalent provision for continuity of NHS continuing care and this creates inequity between people who receive social care and support and people who receive NHS continuing care. Furthermore, some people hold individual budgets with a mixture of funding streams (including personal health budget) and this needs to be covered by portability.

#### ***Ordinary residence (Clause 32)***

Disability Rights UK welcomes the modernising of the ordinary residence rules which should go some way addressing the tendency amongst some local authorities to discharge of their responsibilities as soon a person moves out of an out-of-area placement changes. We would like to draw particular attention to disabled students. They may need one care and support package when they study in another place (e.g. at college or university) and a different package where they live during holiday periods. Often they find themselves caught between two local authorities who dispute about the ordinary residence. The guidance needs to provide clarity about where they will be deemed ordinarily residence while the care and support plan must be flexible to cover the two different packages.

Guidance also needs to clarify how the ordinary residence rules and the continuity of care provisions apply to people of no settled residence, in particular Gypsies and Travellers.

### **Safeguarding adults at risk of abuse or neglect**

Disability Rights UK welcomes the safeguarding adults provisions. Disabled people have a right to be safe, and free from violence and abuse (Article 16 of the UN Disability Convention).

It is important to recognise that strong community networks and effective support will help reduce the risk of abuse.

Whilst we welcome the definition of ‘financial abuse’ as provided by Clause 34(2), this clause gives the impression that it is the only form of abuse. We would suggest that an additional subsection is inserted after 34(1) to state that abuse covers financial, physical, emotional and sexual abuse.

We strongly recommend additional regulations to ensure that an adult who is at risk of abuse or has been abused gets the support of an independent advocate. That is because they are highly likely to need someone to stand by them. An OPAAL/AEA benchmarking advocacy and abuse project found that having an independent, trained advocate working with older people suffering abuse helped reduce or prevent the problem in over 70% of cases.

Regulations also need to place a duty on local authorities to ensure that those carrying out investigations have received adequate training to carry out an investigation of alleged abuse against a disabled person – and this includes being able to listen and take note of the views of the disabled person concerned.

That is because we find that people who carry out investigations may not necessarily have received training which would help them understand specific issues that arise in relation to disabled people (for example, perceived incapacity, bias towards the carer, or lack of skills to communicate effectively with a disabled person, with the support of an independent advocate if so required). This hampers their ability to carry out an effective investigation and it may make a situation worse.

***Transition for children to adult care and support, etc.***

The draft Children and Families Bill makes provision for an 'education, care and health plan' (ECHP) for children and young people up to the age of 25. We are concerned that there is a risk that adult services do not assess someone before their 25<sup>th</sup> birthday – i.e. when the ECHP ends. We recommend that the Care and Support Bill clarifies that adult services will be involved in the development and delivery of the ECHP from the age of 18.

We would welcome clarification how the portability duties relate to transition for children to adult care and support if the child moves from one area to another (e.g. to move out of their parental home or to access education or employment elsewhere). We presume that the child who receives 'care accommodation' will remain the responsibility of the placing authority but this is not clear in relation to a child who receives home or community care services. We believe it may be necessary to amend Clause 31 so that it covers Clauses 39-43.