

Consultation Questionnaire

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 2 : Values and Principles

**Question 1a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

**Question 1b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
x <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 1c: Do you have any further comments on this section of the guidance?

Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

• Within Item 8. 'the Person's Pathway: Roles and responsibilities' we would like to see **a much stronger emphasis on the local authorities' overarching responsibility to apply the guidance within the spirit, principle and values of the act.** It should be spelt out that the choosing and picking approach to the 2007 SDS guidance is no longer an option for local authorities and that a successful implementation of the Act can only happen if they are willing to take on board all aspects of the guidance including co-production, service users' involvement and transparent funding processes.

• We are extremely disappointed that despite the active and supportive involvement of SDSS and a number of its members, including our organisation, in the making of the guidance, Table 2 does not include a specific section on independent information and support organisations. We understand that information and support services are mentioned later in the document, but not being included in this section implies that they are at the periphery of the process when they are actually key to the success of SDS both for individuals and for the strategy implementing the Act. This seriously undermines the Scottish Government's investment - both financially and through resources available to lead the specific National Implementation Group on Information and Support Organisations - to these organisations. **We therefore urge the Government to rectify this in the final version of the guidance and include information and support organisations as a key stakeholder in a successful implementation of the Act.**

If included, we suggest the following paragraph under 'responsibilities':

Information and support organisations have a very important role to play in

ensuring that the supported individual and carer(s), if involved in the process, can make fully informed choices. They also have a key role in enabling the supported person to make the most of his/her care/support. Very importantly, information and support organisations are in a very good position to enable the supported individual to manage his/her support package sustainably and stress free. These organisations also have a very important role to play in supporting people with less capacity to manage their package. In turn they can enable social and health professionals to offer choice and control to a greater number of people.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 3: Values and Principles

**Question 2a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/> x	<input type="checkbox"/>

**Question 2b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/> x	<input type="checkbox"/>	<input type="checkbox"/>

Question 2c: Do you have any further comments on this section of the guidance?

Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

This section of the guidance should **make a clear link with the rights of independent living which underpin the 2013 Act**. It should clearly refer to Section 1A of the Act which asserts the link between the existing rights of individuals and duties placed on local authorities; European Convention of Human Rights, the United Nations Convention on the Rights of Disabled People and the Equality and Human Rights Acts.

By including clearly this in the guidance it will provide local authorities with a greater understanding of Section 1A and the duties placed on them which underline social care/support. It will **give an unequivocal message that access to choice and control of adequate support/care is a universal human right**.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 4: Eligibility and Assessment

Question 3a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/> x	<input type="checkbox"/>

Question 3b: How useful did you find this section of the guidance? (please tick)

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/> x	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 3c: Do you have any further comments on this section of the guidance?

Some advice to help you to answer this question – Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

- We welcome items 23 and 24 of the guidance and the clear message that offering the bare minimum support to individuals is not within the aims and spirit of the Act. We also are pleased to see that local authorities are asked to take a strategic approach to ensuring that those not eligible for care are still supported actively as part of the wider role of investing in prevention and in quality universal services.

• We feel, however, that Scottish Government should use this section (in addition to section 5) of the guidance to clearly assert that **the financial outcome of the assessment and the process by which it is arrived at, should be genuinely transparent and ensure that it is fit for purpose across all groups, impairments and conditions.**

• We have concerns regarding the suggested 'Exchange Model of Assessment' (figure 1 p. 19). This implies that the service user has no more say than the carer or agency. We actually question the role of the agency in an assessment process, unless the assessed person specifically requests it to be part of the assessment. We believe that the same should apply to carers and that the guidance should make clear that carers should be involved at the request of the assessed person.

• Similarly we strongly believe that **the guidance should highlight the conflict of interest of providers (understood as direct care providers) helping with self assessment. The guidance should recommend that the assessed person be sign-posted to independent information and support organisations** that will be best placed to prepare the individual as these organisations will have no self interest in the outcomes of the assessment.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 5 : Support Planning

This section of the guidance covered:

- general guidance on support planning
- risk
- resources
- the choices that must be made available to the supported person and
- information and support

**Question 4a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/> x	<input type="checkbox"/>

**Question 4b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/> x	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 4c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

- It is our experience that support planning is not properly understood by those local authority officers who currently develop resource allocation systems nor by front line social workers who think that identifying personal/individual outcomes with a choice of services to meet them, is support planning.
- We also know that support planning is key into enabling the person to meet his/her outcomes, sustain his/her choices and make the most of them.
- The guidance should therefore make clear that:
 - support planning is a key aspect of SDS that most of the time cannot take place in one interaction with the supported individual
 - supporting people to plan their care/support should be resourced. We suggest that the guidance should highlight that to resource support planning through an individual budget is very tricky and potentially counter productive as it may deter a large number of people from getting support in the first place (in order to save money for direct care/support). We therefore suggest that local authorities should either:
 - take a strategic and co-ordinated approach to support planning by commissioning **independent** information and support organisations to do this. These service should be seen as universal services.
 - Or:
 - allocate funds within an individual budget specifically to be used for support planning
- With 21 years experience in supporting people to plan for their direct payments we know **that support planning spans from a few hours of support to days of close work with an individual, either regularly or broken into manageable sessions.**
- Options
 - Option 1
 - The guidance should make clear that option 1 should be presented with all information about support available to choose and manage the option and systematic sign posting to information and support organisation(s) including CILs
 - The guidance should assert in this section the importance of offering option 1 to

those who may not have the capacity to manage the package financially, but still want the full flexibility offered by the option, by funding a third party organisation to do the financial management on behalf of the individual.

- Therefore the guidance should also make clear that individuals under this option should have a right to identify a third party to receive the DP. This is important because we know that, in Edinburgh for example, some service users are currently told that they cannot do this and they must receive their direct payment on their 'Edinburgh Card'. They are also told that they shouldn't transfer their funding to a 'third party'.

- Scottish Government should develop a more extensive DP guide for local authorities, so that they use it to develop their own local guidance (the lack of this disempowers LAs frontline staff, undermines the effectiveness of systems, produces a 'postcode lottery' situation within the boundaries of the local authorities, confuses the service user and generates unhelpful extra work for support organisations) so that their departments (e.g. communication, commissioning, finance etc.) issue decisions and policies that support personal assistant employers to manage their responsibilities, rather than create extra barriers for them.

Option 2

The use of the term provider in the guidance is misleading. Information and support organisations are not providers as such and yet are in an even better position than providers (no conflict of interest) to be the agencies 'making various administrative arrangements on the supported person's behalf'

Option 3

Right at the outset of the description the guidance should re-emphasise that option 3 is not a 'parking option' and should still enable the individual to meet his/her outcomes.

- Professional discretion to limit the choices available to individuals

As mentioned earlier, and based on our experience we know that social workers are not comfortable offering a direct payment to individuals who have the capacity to choose but not to manage it, although it would work very well for them. The guidance should therefore make very clear that if a person should choose and benefit from using a direct payment to meet his/her outcomes, the social worker should ensure that he/she is offered it with the right support to manage it.

- Given the experience of disabled people and people with long term conditions in some local authorities where individual budgets are being rolled out and where individuals see their support being significantly reduced on grounds of a new RAS, **the guidance should advise local authorities to have and advertise a clear appeal process.**

- We welcome the section on information and support but would advise to:

- make very clear that independent information and support should be accessible at all stages of the pathway

- use the SDSS reference document on what services should be available in each local authority to ensure the proper level of support and information rather than the incomplete table 7

- clearly recommend that local authorities should commission and fund

independent information and support organisations and encourage peer support services

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 6 : Monitoring and Review

**Question 5a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/> x	<input type="checkbox"/>

**Question 5b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/> x	<input type="checkbox"/>	<input type="checkbox"/>

Question 5c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

- The guidance should advise that local authorities make clear to supported people that they have the right to change the way they are supported at any time and that this shouldn't undermine the level of support they receive
- The guidance should clarify that individuals should be signposted to independent support organisations at the time of their reviews so that, if they wished, they could prepare for this and enhance the process with well thought out and informed suggestions.
- The guidance should assert firmly that reviews should not change the basis on which a level of support was agreed but focus on the relevance and level of the support itself in relation to the individuals' outcomes.
- The guidance should firmly advise that the outcome of a review should be communicated to and agreed by the supported person before any changes to the package take place

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 7 : Facilitating genuine choice for individuals

**Question 6a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

**Question 6b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/> x	<input type="checkbox"/>	<input type="checkbox"/>

Question 6c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

- This section is very important and should recommend to local authorities more clearly that they build the capacity of the providers while taking a realistic approach to commissioning. Support packages should reflect the right to pay support/care workers including PAs, some of them with specialised skills, decent fair wages.
- The guidance should strongly advise local authorities' commissioners to carefully analyse the nature of the services they no longer wish to directly fund and fully discuss the changes with the providers. In the specific field of information and support our 21 years of experience demonstrate that when service users know that they can access these services at any time and without a limit on the amount of time, they feel much more confident to become PA employers or change their support to better meet their needs and outcomes. Information and support services should be part of universal services commissioned by the local authorities.
- The Guidance should strongly advise local authorities against using individual budgets to finance services that were not previously funded by the social care budget, unless they have absolute confidence in the way they calculate individual budgets and include the cost of accessing these services in them. It should be reasserted that it would be unfair and discriminatory to force disabled people and people with long term conditions to pay through their budget to access employment or housing support, for example, if this would have to be at the expense of direct care and support that they need in the first place.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 8 : The role of the NHS professional

**Question 7a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

**Question 7b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 7c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

that are more appropriate for statutory guidance rather than Regulations?

The guidance should encourage local authorities and health boards to work much more effectively together on developing joint packages and should refer to the health and social care integration legislation as a unique opportunity to develop effective joint approaches towards SDS.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.1 : Children and Families

Question 8a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/> x	<input type="checkbox"/>

Question 8b: How useful did you find this section of the guidance? (please tick)

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/> x	<input type="checkbox"/>	<input type="checkbox"/>

Question 8c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Based on our experience, children's and families services in local authorities have traditionally not engaged with direct payments in the past and are reluctantly engaging now with great fear and lack of confidence. We believe that the Scottish Government has a role in helping to address this by bringing local authorities, providers and parents of disabled children together. We understand that the latest round of funding to user-led organisations will help toward facilitating this and welcome this.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.2 : Supported decision-making and circles of support

**Question 9a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/> x	<input type="checkbox"/>

**Question 9b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 9c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.3: Carers

**Question 10a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

**Question 10b: How useful did you find this section of the guidance?
(please tick)**

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 10c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

Carers play an important role in care and the Act recognises this. The guidance should make very clear, however, that any funds toward financing this particular duty should not come from a reduction of the funding for disabled people and people with long term conditions.

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.4: Direct payments

Question 11a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

Question 11b: How useful did you find this section of the guidance? (please tick)

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 11c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

If a guide to direct payments is produced this section gives a good basic introduction to DPs for local authorities.

Draft Statutory Guidance on Care and Support

Section 9.5: Wider legal duties and strategic responsibilities

Question 12a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

Question 12b: How useful did you find this section of the guidance? (please

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 12c: Do you have any further comments on this section of the guidance?

Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made or any other comments you'd like to make?

On the issue care charges we strongly believe that charging disabled people for their support and care is discriminatory and against their human rights. Through

our Disability Information Service we are very aware that quite a number of disabled people and people with long term conditions do not live independent lives and rely heavily on family carers because they know (or sometimes just assume) that they would be charged for their care and therefore lose the part of their income that enables them and their family to keep socially connected or because they do not want to involve their spouse's income in the financing of their own support and care.

We are very disturbed to see that Scottish Government and COSLA are happy, for example, to take on board the argument that keeping cultural centres and museums free is a good thing for Scottish society but ensuring that care and support is free at the point of delivery for disabled people, is not.

As an employer of disabled people and people with long term conditions we are very aware that care charges are a disincentive for them to work or work more hours. In our organisation two employees with the same job and working the same number of hours, one disabled and in receipt of care and the other not, will not have the same disposable income at the end of the month.

We therefore urge the Scottish Government to use the guidance to send a clear message that care charges are not in line with the spirit and principles of the Act, and that the administration of care charges, given the flexibility of the support and greater use of community services combined with the closer relationship between health and support/care services, will become too complex and expensive to administer to remain an option.

Draft Statutory Guidance on Care and Support

Consultation Questions – General Questions

The Guidance document as a whole

Question 13: Do you have any further general comments on the guidance?

For example, are there any gaps in terms of the topics covered by the guidance? Are there any major changes that you would recommend? Do you have any comments on the style and layout of the guidance, or the language used in the guidance?

We feel that the guidance should place much greater emphasis on the importance of training at all levels of a local authority, and strongly advise that service users and their organisations be involved in the training process.

The costs and benefits arising from this guidance

Question 14: Do you have any comments on the financial costs or benefits of the requirements set out in the guidance?

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the guidance. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

Comments

The equality and human rights impacts of the guidance

Question 15 (a): Do you have any views on the impact of the guidance on any or all of the following equality categories:

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**
- v) race, and;**
- vi) religion and belief**

Some advice to help you to answer this question - By “equality impacts” we mean whether or not the guidance will affect certain groups in a positive or a negative way. In considering the impacts you may wish to consult the Equality Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/9876>

We plan to update the Equality Impact Assessment in light of the comments and information from this consultation.

Question 15 (b): Do you have any views on the impact of the guidance on human rights?

For more information about human rights please see the Scottish Human Rights Commission’s website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

As mentioned previously, we feel that neither the Act nor the guidance clarify well enough that SDS is a right and therefore that local and health authorities should prioritise investment and funding to people and organisations that support service users to take up that right.

Consultation Questionnaire

Draft Regulations

Consultation Questions

Question 1: What are your views on Part 2 of the draft Regulations (calculation, payment and termination of direct payments)?

A consistent approach to direct payment is important. It is, however, undermined by the diverse nature of policies associated with means tests. We welcome Regulation 6 allowing a third party for option 2, especially when some local authorities are preventing organisations from being a third party in supporting the individual with his/her direct payment at present.

Question 2: What are your views on Part 3 of the draft Regulations (appropriate/inappropriate circumstances for the employment of close relatives)?

Based on our experience and practice we are very aware of the relevance of employing close relatives in some circumstances. We also however witness how it can defeat the very purpose of enabling 'normal' relationships between individuals, by imposing a 'carer to - cared for' relation between individuals. We have also witnessed some service users having difficulty remaining in control of their support and struggling to take difficult decisions as an employer because their employee was a partner or a member of the family.

Question 3: What are your views on Regulation 11 which deems individuals who are placed under a variety of criminal justice orders to be ineligible to receive direct payments?

For example, is it appropriate to impose the exclusions listed in Regulation 11? Are there any persons not listed in regulation 11 to whom it would be inappropriate to offer the option of a direct payment?

We agree with the listed exclusions

Question 4: What are your views on restricting access to direct payments for those who are homeless, those who are fleeing domestic abuse or those who require support in relation to drug or alcohol addiction?

This being outside our field of expertise we feel that local authorities should engage with the voluntary sector on these issues to find the right solutions

Question 5: What are your views on restricting access to direct payments in relation to the provision of long-term residential care?

This question was raised during the initial consultations on a draft SDS Bill. The Scottish Government would like to invite detailed views before making a final decision prior to the laying of the Regulations before the Scottish Parliament. Should the restriction be removed from the final regulations, thereby allowing direct payments for residential care? Or should it be retained? Please provide reasons as to your support or opposition to requiring authorities to provide direct payments for residential care.

Although we feel that DPs should enable people to have choice and control over their residential care we are also aware that, in the short term at least, destabilising the residential care market may have a great impact on its cost, which therefore may result in discriminating even more against people on low incomes.

Question 6: The draft Regulations do not specify circumstances where the direct payment option should be unavailable for care and support to children/families. *Should* there be specific restrictions on choice of support in relation to children/families support (i.e. support provided under Section 22 of the Children (Scotland) Act 1995) and should these restrictions apply to the direct payment only, or to other options as well?

We feel that this particular piece of regulation should be further discussed with the different stakeholders in order to differentiate risks from fears and sheer lack of understanding.

Question 7: Do you have any further comments on the draft Regulations?

For example, are there any gaps in terms of the topics covered by the Regulations? Are there any major changes that you would recommend? Are there any topics that are more appropriate for statutory guidance rather than Regulations?

Draft Regulations

Consultation Questions – General Questions

The costs and benefits arising from these regulations

Question 8 : Do you have any comments on the financial costs or benefits of the Regulations?

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the Regulations. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

Comments

The equality and human rights impacts of the regulations

Question 9 (a): Do you have any views on the impact of the Regulations on any or all of the following equality categories:

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**
- v) race, and;**
- vi) religion and belief**

By “equality impacts” we mean whether or not, and in what ways, the Regulations will affect certain groups, and whether they will impact on those groups in a positive or a negative way. In considering the impacts you may wish to consult the Equality Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act 2013, available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/9876>

We plan to update the Equality Impact Assessment in light of this consultation.

Comments

Question 9 (b): Do you have any views on the impact of the Regulations on human rights?

For more information about human rights please see the Scottish Human Rights Commission’s website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

We feel that as they stand the regulations have a weakened impact on promoting the human rights of disabled people. The regulations should clearly refer to Article 19 of the United Nations Convention on the Rights of Disabled People (UNCRPD) which states that ‘disabled people have a right to live in the community, with the support they need and can make choices like other people do’

What follows is the collated output from a face to face consultation event where LCiL staff elicited feedback on the broad themes of the SDS guidance from 11 disabled people and two carers through small group discussions.

We're aware that some of what they say they want to see covered in the guidance is already present in the current draft of the guidance. We have still included those comments here so that it is clear what the people we consulted thought was important.

General themes

Information

People said a lot about how the guidance should encourage local authorities to develop and demonstrate good practice in giving information to people accessing, or trying to access, social care:

- Information should be clear, simple and jargon free
- Social workers should present the options in a positive way, and explain fully what support is available for people to manage each option
- They should offer case study examples of how others went about accessing support, how they made decisions about what was best for them and examples of financial breakdowns of what support someone accessed within each of the options
- There should be clear and simple routes so that people know how to complain or give feedback to the local authority

There were also comments on signposting from outside the local authority:

'The professionals (for example doctors, nurses) who are in touch with the person have a big role to play in signposting the individual for support including to social care, but also to where to get help for the care of the children of the supported person. Primary care professionals should know about the help out there. This guidance should be for them too.'

and about signposting people elsewhere when necessary:

'The guidance should be clear that if a person doesn't meet the eligibility threshold the professional should still signpost to any other support that is available outside the local authority (and

social workers need to be aware of what other support is available in their area).’

‘A clear idea of where to go to to talk things through, for example a local support organisation.’

Rights

People said strongly that they want the guidance to make clear that support is a right:

‘Everyone should know that it is a right to be supported.’

‘You have to be very clear that it is a right to ask for and receive support. You shouldn’t be made feel a burden. It is important that the social worker puts this in the right way right at the start. It is very important how the social worker or occupational therapist puts the whole thing over. For this professionals must be well trained’

‘It is important to reinforce that the person is not a burden when the person goes for an assessment and the assessment shouldn’t be seen as a way of alleviating the burden of another, but as a right to be supported.’

Independent support and advice

Throughout the consultation people stressed that they needed independent support as they travel along the supported person’s pathway, and that the importance of referring people to independent support organisations should be made clear in the guidance.

‘Local Authorities should understand the role of their local support organisation, and that they should be involved at every step of the way (for example joint visits), that they should refer to the local support organisation or CiL as early as possible.’

‘Support organisations must be at the start and through the whole pathway. They can build the confidence of the individual who can then gently challenge the social worker if he/she dismisses or ignores an option.’

‘It is very easy for a social worker to put people off applying for a particular option, for example because they assume that the person is not able to manage it. An independent organisation would give all the options.’

‘To choose agencies people need independent information, and feedback from other service users. But some people will also need help with interviewing them and deciding which agency to go for. Independent support is important to make the right decision.’

‘An individual budget puts a lot of responsibility on the person managing the package to maximise it. There’s a need for an independent organisation to help with this if the person does not have the capacity to do this.’

‘For those who are not so articulate, assertive or don’t know what they don’t know they should have access to support to prepare for the review with support organisations.’

Peer support

As well as independent support and advice people said that peer support should be encouraged through the guidance:

‘It enables you to say the intimate and sensitive things about you and your condition. You know you will be understood’

‘The guidance should inform local authorities that a good place for people to find out what support is available is ‘word of mouth’ from others who already use support – for example peer support, local disabled people’s organisations.’

‘Local authorities should facilitate local champions – people with experience of planning their own support as this will encourage others to do the same.’

Joined up working and single points of contact

People told us that it was unacceptable to have to tell the same story to several professionals:

- when they moved from NHS services to local authority services

- because they saw a different member of local authority staff each time
- because a supported person and their carer had two different professionals dealing with them

‘The duplication of assessment when someone moves from hospital back home can be onerous for the supported person. NHS and social work professionals need to be joined up.’

They want the guidance to say there should be a single point of contact within the local authority, and that contact should be made easier overall:

‘The advice to local authorities should be to establish a relationship with the person at the centre.’

‘Social work should be easy to contact at all times, not just short set hours and then otherwise for emergencies’

‘There should be a named person for people to phone with any questions’

‘There should be consistency in who you speak to (ideally one person) and what information is given’

‘The review should be done by the social worker who set up the package.’

‘Social workers must come to the reviews prepared. They must have all the right paperwork to refer to (such as the person’s support plan) and they should not have to ‘start from scratch’ asking the same questions at every review as this can be stressful and onerous for the individual.’

Time

People talked about the importance of being given enough time to digest and understand information at all stages of the process.

They also stressed that the imbalance in the power relationship (a local authority worker making decisions that have a major effect on the life of the supported person) means that assessment and planning can be causes of great anxiety and that time to prepare, think and discuss with

family, friends or independent support organisation staff is vital if the supported person is to be empowered and able to interact in the more equal way expected in co-production.

‘People need plenty of time for assessment – either a few shorter meetings or one longer one’

‘People should be given time to digest the options and ask questions’

‘It is important that the supported person (and carers) take the lead in discussing types of support. The professional should be listening to what kind of support the person wants.’

Specific stages of the person’s journey

Assessment

People want the guidance to stress that assessment should be tailored to their own specific circumstances, look at their life in the round and involve other people who **they want to be involved** (this may include carers, other family members or independent support workers).

‘Assessment is a conversation not a tick box exercise. It should be tailored to the individual – for example an assessment for someone with mental health problems should not be the same as for an older person. It should never be a ‘one size fits all’ assessment.’

‘People should be given plenty of information at assessment, all the options should be explained in full and people should be given time to digest the options and ask questions.’

‘Workers need to have a good understanding of fluctuating conditions.’

‘It is important that assessment involves people other than just the supported person and social worker (carers, advocates, support organisations) – the assessment should involve anyone that the supported person wants.’

‘Workers need to understand the role of circles of support and be confident in using this as an option.’

‘Assessment should take the whole family situation into account. If a family member gets sick or is under a lot of stress this will have an impact on the supported person.’

They also want the guidance to stress that people may need to be reassessed if things change – especially when they move on from acute or emergency care:

‘The guidance must be clear on the journey from emergency care to long term care. It should explain that re-ablement and intermediate care is **short term** and the goal should be to arrange long term support that helps the person to feel safe and reach their outcomes.’

‘People need to know that they can ask for a reassessment if their circumstances have changed.’

Outcomes

Most people found outcomes difficult to grasp and were concerned that local authority staff would too. They want the guidance to give clear instruction on what outcomes are and real examples of outcomes in practice. They were also sceptical about how eligibility for ‘critical or substantial’ needs could be translated into outcomes that would genuinely result in independent living.

‘Outcomes should be explained as getting people to think about what they want to be able to do, this needs to be in Plain English as lots of people struggle with the terms outcome’

‘There should be a lot of case studies and different examples of outcomes, but not an exhaustive list.’

‘Something about how to measure outcomes making it very clear that getting up, being washed and being fed are not outcomes’

‘For some people with reduced mobility feeling safe at night is a very important aspect of their wellbeing. Will it be seen as an outcome? Most of the time this would mean having a person staying at the supported person’s home at night. Given the size of the packages nowadays it could be seen as unaffordable or is it

going to be costed at the expense of hours of support needed to do things?’

‘The guidance should tell the local authority that living your life ‘safe’ is not a way of life for many.’

‘The guidance should tell social workers that sometimes supporting a person’s less obvious needs can have a positive effect. For example someone might have a physical disability but also be really stressed. Supporting them to be less stressed can have a positive impact on their other needs.’

‘It is important that the supported person (and carers) take the lead in discussing types of support. The professional should be listening to what kind of support the person wants.’

Choice of option

People want the guidance to stress the need for local authority staff to explain and offer all four options fully, without exerting influence on the supported person to take (or avoid) a particular option. Again there was scepticism about this as people had past experience of direct payments being talked down or not offered at all.

‘Local Authorities and their workers should know that they must explain direct payments clearly to people and answer their questions about them. They need to know that they should promote direct payments in a positive way.’

‘Currently direct payments are offered in a negative way, the guidance should underline to social workers the importance of presenting options in a positive way.’

Budget

People want to know that the guidance will result in transparency about both how much money is available for their support and the process used to decide the amount.

‘People who want to should understand how an individual budget is calculated. What costs will be taken into account if one option or the other is chosen.’

‘Social workers should explain how maintaining personal care, which is not an outcome in itself, but is a key element of support for many disabled people, will be costed into the package.’

There were concerns about local authority staff being put in a position where there was a conflict of interest between the spirit and principles of the act and the authority’s need to balance its books:

‘Social workers have a conflict of interest. They know they have to go back to their manager, who will say ‘we cannot fund this, we cannot fund that’. This is clouding their judgement.’

‘Social workers should be made clear that they shouldn’t influence for a particular option. However, some options will be more expensive than others (for example a direct payment to employ personal assistants may be cheaper than option 2 using an agency) – they will have a conflict of interest.’

People also want the guidance to make clear that independent support shouldn’t be paid for from individual budgets:

‘The guidance should say that the support from local organisations shouldn’t be paid through individual budgets (are social workers paid directly by service users?). If people use their individual budgets for this there would be a too great a risk of people hesitating to get the advice and information and not making the right decisions.’

Review

People want the guidance to spell out when and how reviews should be carried out, and that they should be an opportunity for the supported person to give feedback and have changes made to their support if needed.

They also want the guidance to make clear that a review shouldn’t be used to cut the person’s level of support.

‘To make review worthwhile, there needs to be good communication, it shouldn’t be too formal, and it should not just be a ‘tick box exercise’. It must be personal and any necessary changes followed up.’

‘People shouldn’t be frightened of asking for a review, which they often are as they worry it will mean their package will be reduced or changed in ways they don’t want.’

‘The focus should never be on cutting the package at a review – it should be on asking the person: what is working well and what isn’t?’

‘The primary purpose of the first review should be to find out if anything is going wrong – it should help the person to feel safe and supported.’

‘The guidance should provide advice to social workers on the timing of the first review – people need sufficient notice and time to think about their situation before the first review takes place.’

Making a change

Finally, people told us that the guidance should make clear that people can change the option they have chosen, or use their budget in a different way, as their circumstances or confidence change, and that there should be the opportunity to do this when it suits them, rather than at a time set by the local authority.

‘Social workers need to know that people may wish to change their option and take more responsibility – even if their current support is working well.’

‘People need to know that they can change their mind about the option they use.’

‘It needs to be clear that if you choose one option or a particular service and it doesn’t work out then you can speak to your social worker and change your support. No support is guaranteed to work.’