

Consultation Response: Consultation on Carers Legislation (April 2014)

This is a response to the Scottish Government's Consultation on Carers Legislation by Inclusion Scotland (IS) and Self Directed Support Scotland (SDSS). It draws on evidence gathered by GDA, ILiS Project, Inclusion Scotland, SDSS member organisations and the lived experience of disabled people in receipt of social care and support in Scotland.



SDSS www.sdsscotland.org.uk is a national membership organisation which actively promotes Independent Living by supporting, working with, and championing the aims of Self Directed Support disabled people's organisations.



Inclusion Scotland (IS) www.inclusionscotland.org is a network of disabled peoples' organisations and individual disabled people. Our main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people's everyday lives and to encourage a wider understanding of those issues throughout Scotland.



The Independent Living in Scotland (ILiS) www.ilis.co.uk project aims to support disabled people in Scotland to have their voices heard and to build the disabled people's Independent Living Movement (ILM).

Independent living:

Disabled People have defined independent living as:

“disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”.

Independent living is about more than having control and choice for the purpose of self-management of your condition. This definition has been endorsed in the ‘Vision for Independent Living’ by the Cabinet Secretary for Health for Scottish Government, COSLA, the NHS in Scotland and the Scottish Independent Living Coalition¹.

1. Introduction

Joint statement by Disabled People’s Organisations:

We welcome and support legislation for carers. Changes in legislation affecting carers will impact on disabled people and others who are ‘cared for’. Decisions on carer’s legislation cannot be take in isolation. It is in this context we contribute to this consultation.

Disabled people and their directly accountable organisations call upon the Scottish Government to take account of:

- The representation of disabled people by Disabled People’s Organisations when developing and implementing carers legislation
- How changes in carers legislation may impact on disabled people and their social care and support
- Ways to ensure equity between service users and carers social care and support
- How statutory and non-statutory eligibility criteria would impact on disabled people and carers
- The impact of charges on service users and carers; and
- Portability of social care packages for service users

1.1. For those people who use it – including disabled people – social care and support is an example of the essential practical assistance and support needed to participate in society and lead an ordinary life (see the definition of independent living above). Without such support, disabled people and other social care users cannot enjoy their human rights on an equal basis to non-disabled people. As such, social care is an essential infrastructure for the equality and human rights of disabled people and others who use social care and support.

¹ <http://www.scotland.gov.uk/Publications/2013/04/8699>

- 1.2. Carers providing unpaid support have a crucial role to play in the way we provide social care and support as a society and any legislation to support them will impact on disabled people. It is in this context that we are responding to this consultation.
 - 1.3. Disabled people welcomed the Social Care (Self-directed Support) legislation recognises the rights of disabled people and carers to care and support.
 - 1.4. To face the significant challenges ahead, the progression of social care and support in Scotland needs to be co-produced with disabled people and carers². We believe that the Scottish Government's proposals for carers and subsequent legislation presents an opportunity to do this and so should be based on the views of all individuals, including disabled people, in receipt of social care and support.
 - 1.5. In addition to our overarching statements above, this response does not cover all the consultation questions. Instead, it concentrates on those issues which are of significance for disabled people, in order that the Scottish Government can consider the views of all participants in receipt of social care and support and take a rounded view of care and carers needed for the full success of the legislation proposed.
 - 1.6. In this context, we note with caution the language and tone used in the document to describe the 'cared for person.' This is inconsistent with much other policy that affects disabled people and other users of social care. As Disabled People Organisations we can support the Scottish Government to achieve consistency and accuracy in the use of language to describe disabled people, service users and their representative organisations, by working in coproduction with them, on this (and other) issues.
- 2. The Carer's Assessment (the Carer's Support Plan) (Chapter 2)**
- 2.1. Disabled People's organisations welcome proposals to provide support to carers. This needs to be in the context of the primary purpose of care and support which is to provide practical support to enable the "cared for person" to participate in society and live an ordinary life. We recognise the carer too should be supported to participate in society and live an ordinary life.

² <http://www.ilis.co.uk/get-active/publications/co-production-toolkit>

- 2.2. This is consistent with the principles adopted for health and social care integration (in the Public Bodies (Joint Working)(Scotland) Act 2014) and for Self-directed Support (Social Care (Self-directed Support)(Scotland) Act 2013).
- 2.3. **It is important, therefore, that the carers support plan, whilst addressing the needs and aspirations of the carer, also takes account of the needs and aspirations of the “cared for person”. The best way to achieve this is to ensure that social care and support packages and carer support plans are developed together in co-production with the carer, the “cared for person” and the statutory authorities, with the aim of supporting independent living for both parties.**
- 2.4. Developing support packages in coproduction will also allow consideration of whether the role of the carer has developed out of choice or necessity. The partner or close relative has to take on the functions of a carer because there has been no adequate or affordable social care package available.
- 2.5. We recognise that in many cases the cared for person will prefer to receive care from their partner or relative, and that the partner or relative will prefer to provide the care. However, there will also be cases where given a fair choice between “carer” or an adequate and affordable “social care package”, both carer and “cared for person” would prefer the social care package option.
- 2.6. The partner or relative in the role of carer may have gradually taken on a more intensive role as the “cared for person” requires more extensive support. It may be more difficult to detect when the balance between being a partner or close relative who willingly provides some support and being a full-time carer changes.
- 2.7. We welcome the recognition by Scottish Government that assessment’s in social care and support varies in quality between local authorities. Practice between local authorities also varies in that similar impairments are assessed and resourced differently by local authorities.
- 2.8. As DPOs we have long argued for national standards in criteria, eligibility and assessment for social care – for disabled people- and for carers. National criteria would ensure a fair and equitable application of social care and support across Scotland. Please see our response to question 7 for further information.

- 2.9. As DPOs we note with concern the Scottish Government does not collect data on the number of assessments carried out and relies on anecdotal information (paragraph 7). We believe it is important to collect the information to ensure adequate funding of social care and support, for local authorities to adhere to the Equality Act 2010 and to ensure services are located where communities need them.

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services?

Question 5: Should we remove from statute the wording about the carer's ability to provide care?

- 2.9 We support improving the rights of all individuals to social care and support, including carer's rights. However, we note with caution the "removal of other existing criteria." in particular Part 12. Further consultation is required with all stakeholders in coproduction³, including DPOs, on the feasibility, practicality and reasonableness of changes to the criteria.

Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?

- 2.10 Please see our response 2.9. We welcome the Scottish Government's recognition of the issue of delays in assessment for individuals. Service users and our member organisations inform us of the impact significant delay has on individuals and their families.
- 2.11 DPOs note there is no equivalent duty to support service users. Therefore, we strongly recommend the Scottish Government use its powers to ensure every individual in the self-directed support process is treated equally.

Question 7: How significant an issue is portability of assessment for service users and carers?

Question 8: Should the Scottish Government and COSLA with

³ <http://www.ilis.co.uk/get-active/publications/co-production-toolkit>

relevant interests work together to take forward improvements to the portability of assessment?

- 2.12 We welcome the Scottish Government's recognition that "there are issues to be addressed about the portability of assessment, primarily for service users". We welcome this acknowledgment, which echoes what we understand from the direct lived experience of service users.
- 2.13 Freedom of movement is a basic human and economic right, it is a right that disabled people do not presently enjoy. Article 19 of the UN Convention on the Rights of People with Disabilities (the Disability Rights Convention) says that disabled people have the right to choose where they live.
- 2.14 As DPOs we welcome the assurance that, if portability emerges as an issue from this consultation, DPOs will be invited in to discussions with the Scottish Government and COSLA on how the portability of care and support packages will be improved. We strongly recommend to Scottish Government these joint discussions take place before the policy agenda has been agreed.
- 2.15 Service users and our member organisations tell us, portability is a substantive issue in the continuity of care and support across Scotland.
- 2.16 Without good social care, many disabled people cannot; participate in society on an equal basis to others; they cannot enjoy the right to a family life or to live free from inhumane or degrading treatment; they cannot live their life in the way they choose, at home, at work and in the community or live a productive life. Changes to portability rules are necessary for and underpinned by the human and civil rights of disabled people.
- 2.17 Continuity of this care and support for disabled people who relocate to another local authority is essential. However, at present the rules that determine who will pay for care and support when someone moves from one local authority area to another:
- are confusing;
 - they are unclear on roles and responsibilities
 - are largely open to wide interpretation and thus applied variably and with huge amounts of discretion that can leave the individual with uncertainty on what to expect give no direction on timescales; and

- offer no protection on levels of support or type of service

- 2.18 To be consistent with the policy intentions for a joined up, seamless and efficient system of health and social care support, disabled people believe health and social care legislation must be amended to place duties on local authorities to work together to ensure that when both carers and disabled people move, they have equivalent care and support in place on arrival. Please see appendix for specific suggested amendments to legislation on the portability of assessment.
- 2.19 Legislation must be drafted in such a way that recognises those people who have already been assessed as needing ongoing care and support in one area still require that support, to a similar – or the same – level in another area. People should be entitled to receive support, to a similar level when they move, without any gap in provision.
- 2.20 The risk of interruption to their care needs effectively restricts their ability to move. In some circumstances. Whilst guidelines exist to prevent this, evidence from service users, professionals from local authorities and support organisations suggests that they are wholly inadequate⁴,
- 2.21 **Only the imposition of clear legal obligations will ensure that both carers and disabled people have equal freedom of movement. We urge the Scottish Government to address the issue of portability in this legislation – for both carers and disabled people alike. As DPOs we believe a decision on portability cannot be made solely for service users or carers.**
- 2.22 Amending the legislation would benefit all disabled people and carers whose care and support is funded by their local authority. It would liberate them and their relatives from fears that they will lose their care and support should they choose move.
- 2.23 We recognise that much has been done to align social care and support assessments and charging regimes across local authorities using benchmarking, transparency and collaborative working. However, a significant variation in support provision and charges for it, still exists.
- 2.24 This suggests that such an approach short of legal imposition, valuable as it may be, does not guarantee co-operation between authorities to

⁴ VODG (October 2010) 'Not in My Backyard', available at http://www.vodg.org.uk/uploads/pdfs/VODG_report_final.pdf; and NUS (2010) Life Not Numbers.

ensure seamless and timely transition; nor does it address the long delays that commonly occur in agreeing a care package. There is also no legal requirement or, indeed, any financial incentive on the new authority to implement the care package in a timely way. Amending the legislation would resolve these shortcomings.

- 2.25 On the 11th of May 2011, the Law Commission published recommendations for a new adult social care statute in England to replace existing legislation. With regards to portability they recommended an enhanced duty to co-operate between local authorities. This supports the approach we suggest for the amendment⁵.
- 2.26 We believe that overall, an amendment to the legislation on portability, would be cost neutral. Although some councils may incur additional expenditure as disabled people move into their area, those same councils may have reduced expenditure when disabled people in their area move to other councils. This would just simplify the arrangements and make the transition quicker and fairer. It would ease the cost of administration for councils and avoid costly disputes.
- 2.27 In fact it is our belief that there are significant savings to be made from information-sharing between authorities and simpler reassessments. Greater savings would be delivered if consistent criteria for assessment were used across the country and would stop the need for temporary, inappropriate support being put into place until permanent solutions are assessed for an individual.
- 2.28 At a macro-economic level the increased mobility of disabled people would (as with all workers) facilitate greater employment opportunities, thereby saving on social security benefits expenditure and enhancing the economic competitiveness of the UK.
- 2.29 **Changes to legislation on portability would encourage the movement of disabled people from residential care into an independent living environment, which would reduce public expenditure. It would also advance the Government's vision for independent living in Scotland⁶.**

⁵ Law Commission (May 2011) Adult Social Care. Law Com No 326. Available at <http://www.justice.gov.uk/lawcommission/publications/1460.htm>

⁶ <http://www.scotland.gov.uk/Resource/0041/00418828.pdf>

- 2.30 Statutory and practice guidance would need to be issued to support local authorities in the implementation of the amendments provisions and disabled people's organisations are ready and willing to work with the Government to coproduce these.

3 Support to Carers (Chapter 4)

Question 9: Should we introduce a duty to support carers and young carers, linked to an eligibility framework.

- 3.1 We do not object in principle to establishing a statutory duty to support carers. We note that the Scottish Government intend to establish statutory eligibility framework that would require local authorities to support carers on a consistent basis across the country (paragraph 4.5).
- 3.2 However, at present there is no such statutory eligibility framework for social care of service users. Although there is national guidance on eligibility criteria – critical, substantial, moderate or low – each local authority can set its own definition of these criteria and what, if any, the level of support it will provide. This has led to significant inconsistency in the support and care packages available to disabled people in different local authority areas (see paragraphs 2.12 – 2.29 on portability), and also in the level of charges imposed on disabled people for social care.
- 3.3 This also highlights the inconsistency in the proposal that services provided to a carer as part of a carer's support plan will be free, those supplied to the "cared for person" may be charged for. We do not oppose services to carers being provided for free, but believe that this principle should also apply to all social care services.
- 3.4 The consultation recognises that the carer's needs could be met (wholly or partly) by the provision of services for the cared for person. Could this lead to the perverse situation where a social care service is provided free to one person as part of a carer's support plan but charged for when provided to another person as part of a social care package?
- 3.5 This will add to the inconsistency and injustice that already exists, for disabled people and that will be further complicated by health and social care integration which will lead to integrated packages that may have

some services which are free (health) and some that can be charged for (social care).

- 3.6 One further concern is that as Carer Support Plans will be statutory, they will take precedence over social care packages, which are discretionary, when allocating budgets. Social care packages have already been squeezed as a result of budget cuts, leading to higher eligibility criteria, cuts in individual care packages and charges increasing well in excess of inflation. We call upon the Scottish Government to consider the policy changes carefully in coproduction with DPOs.

4 Carer Involvement (Chapter 6)

Question 14: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

Question 15: Should we make provision for the involvement of carers' organisations in the planning, shaping and delivery of services falling outwith the scope of integration?

Question 16: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support from themselves in areas not covered in existing legislation?

Question 17: What are your views on making provision for young care involvement in the planning, shaping and delivery of services for cared for people and support for young carers?

- 4.1 The principle of coproduction should apply in all of these areas.
- 4.2 It is important to remember, however, that the views of the carer may not be the same as the views of the "cared for person", and it should not be assumed that the carer is speaking for the "cared for person".
- 4.3 **Wherever possible, the cared for person should be involved, in coproduction, in their own right. This is the underpinning ethos of the self-directed support legislation. Changing the balance would undermine the self-directed support process.**

5 Planning and Delivery (Chapter 7)

Question 19: Should we introduce statutory provision to the effect

that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers' strategies which must be kept under review and updated every three years?

5.1 Please see our response in 2.7 – 2.9.

6 Carer and Cared for Person(s) in Different Local Areas (Chapter 9)

Question 27: Should the Scottish Government with COSLA produce guidance for local authorities?

6.1 Please see our response at 2.7 – 2.9 and 2.12 - 2.30.

6.2 We also believe that any guidance that is produced is developed in coproduction with all stakeholders including DPOs.

Appendix

Proposals for a statutory duty on portability of social care.

- 1.1. **Application of the duties:** A clause to set out when the authorities would be subject to the duties in the Bill. The duties would apply when (1) a service user (as referred to in the Bill) is ordinarily resident in one authority (could be described as “the first authority”); and (2) he or she receives a care package from the authority; and (3) he or she wishes to move to become ordinarily resident in another authority (“the new authority”) and to continue to receive a care package. It would cover situations where the individual moves from one authority to another or from residential care funded by one authority to a community living arrangement in another authority. It would not cover situations where the individual stays in another authority for a prolonged period of time but does not intend to become ordinarily resident there.
- 1.2. **First authority: duty to give notice:** A clause to place a duty on the first authority to notify the new authority as soon as it is aware that the individual has a firm intention of becoming ordinarily resident in the new authority.
- 1.3. **New authority: duty to make provision:** A clause to place a duty on the new authority to take steps to put a new care package in place. A care package would take the form of the options for provision set out in the SDS Act 2013. The package must initially be equivalent to the previous package, to ensure that the individual is not worse off. This means that he or she would retain an equivalent personal budget or equivalent services when they move. ‘Equivalent’ would be defined as ‘having the same outcome’.
- 1.4. **First authority: duty to continue funding:** A clause to place a duty on the first authority to continue funding a package equivalent to what it was previously funding, while the new authority is getting a new package in place. There would also need to be provision to ensure the first authority a right to reimbursement for the funding it provides during the transitional period. This should encourage the new authority to take steps to put a new care package in place as quickly as possible.
- 1.5. **Co-operation between the authorities:** A clause to place a duty on authorities to co-operate so that the arrangements are effective and assist in the continuity of care for a disabled person. This would include principles to strengthen the duty of co-operation in a way that would

emphasise the welfare of the individual is paramount; that the arrangements should be timely and seamless; that any dispute between the authorities or one authority and another party (for example, a care provider) should not adversely affect the person's care needs; and that the person's dignity, choice and control should be respected. These principles would encourage authorities to carry out the arrangements in a way that secures the minimum of disruption to the care and support of the individual before, during and after the relocation. They would also ensure that the individual's human rights are respected in accordance with the Equality and Human Rights Commission.

- 1.6. **Regulations:** A clause to enable Ministers to make regulations (in coproduction with service users) in relation to these provisions. The regulations may specify, among other things, the form and content of a notice from one authority to another and the timescales with which the authorities are required to conform, and provide for payment of interest and dispute resolution.