

# **Carers' Legislation – Consultation on Proposals**

**The Scottish Disability Equality Forum (SDEF) works for social inclusion in Scotland through the removal of barriers to equality and the promotion of independent living for people affected by disability.**

**We are a membership organisation, representing individuals affected by disability, and organisations and groups who share our values. Our aim is to ensure that the voices of people affected by disability are heard and heeded within their own communities and at a national and political level.**

**Our Respondent Information Form can be found at the end of the document.**

## **General points:**

- SDEF, alongside the other Disabled Persons Organisations, welcomes and supports legislation for carers.
- Changes in legislation affecting carers inevitably impact on disabled people and other service users who are 'cared for'. They cannot, therefore, be made in isolation; they must be co-produced with disabled people and other service users.
- We ask that terminology is aligned with the Social Care (Self-directed Support) (Scotland) Act 2013 and that the pejorative term 'cared for person' is replaced by 'supported person'.

## **Answers to specific questions**

**Before completing this response, SDEF polled its members, made up of individuals and Access Panels, with a shorter version of this consultation. We have used these to help develop our response.**

**We support the joint response to this consultation submitted by the DPOs Inclusion Scotland and Self Directed Support Scotland. We have highlighted our particular support for elements of their response within ours.**

### **The Carer's Assessment: Carer's Support Plan**

**Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?**

Yes.

There was unanimous support from SDEF's members for this change.

**Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?**

Yes.

The majority of respondents to SDEF's survey supported this change.

**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?**

Yes.

There was unanimous support for this change, with one respondent noting:

'I welcome the change of conditions a carer must currently meet as it excludes a carer looking after an elderly person full time who may be frail and is fully supported by the family. They would have the same or possibly greater needs than a carer who is in receipt of community care.'

**Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?**

Yes.

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

Yes.

One respondent noted that:

'If a carer feels that they need help then that help should be given regardless of any need for an assessment of the carer's ability.'

We note the proposal in Chapter 2, Para 14 to 'Introduce an outcomes-based approach so that the Carer's Support Plan must consider the outcomes that the carer wishes to achieve both in day-to-day life and in the future.'

We agree with the other DPOs that it is important that the Carer's 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 packages and Carer's Support Plans are developed together in co-production with the carer, the 'cared for' person and the statutory authorities, with the aim supporting independent living for both.

Developing support packages in co-production will also allow consideration of whether the role of the carer has developed out of choice or necessity. It may be that the partner or close relative has had to take on the functions of a carer because there has been no adequate or affordable social care package available.

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 having a carer or social care package, neither the carer nor the 'cared for' person would choose the carer option.

**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?**

Yes.

The majority of respondents supported this change, but there was concern raised about the length of time this could result in the carer waiting. One respondent noted:

'A carer should not have to wait indefinitely for a Carer's Support Plan, as they may have needs that require addressing immediately.'

SDEF notes, along with other DPOs, that there is no equivalent duty to those being assessed for social care. We call for the Scottish Government to use its powers to ensure every individual in the self-directed support process is treated equally, whether a carer or 'cared for' person.

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

SDEF agrees with other DPOs that decisions on portability cannot be made solely for service users or carers. Every individual in the self-directed support process should be treated equally, whether a carer or 'cared for' person.

The continuity of care and support for disabled people who relocate to another local authority is essential. 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
- offer no protection on levels of support or type of service

We agree with other DPOs that there should be an explicit recognition that people who have already been assessed as needing ongoing care and support in one area will still require the same, or similar, support in

another area. The current risk of interruption in the support necessary to meet their care needs can present a barrier to disabled people's ability to move.

No measure short of legislation on this matter will guarantee co-operation between two authorities, ensure seamless and timely transition, and address the long delays that commonly occur in agreeing a care package. There is currently no legal requirement or financial incentive on the new authority to implement the care package in a timely way. Amending legislation is the only way to resolve these shortcomings

**Question 8: Should the Scottish Government and COSLA with relevant interests work together to take forward improvements to the portability of assessment?**

Yes.

Disabled people and DPOs, as people with a 'relevant interest', should be an equal party in discussions with the Scottish Government and COSLA as to how the portability of care packages will be improved.

## **Information and Advice**

**Question 9: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?**

Yes.

There was unanimous support for this measure, with respondents noting that:

'Local authorities are probably the best organisation to have a structure which looks after Carer's [and] 3rd Sector inputs must be recognised.'

'These changes should make it easier for carers to access services.'

SDEF believes that an important side benefit of such a duty would be the ability for carers to benchmark the provision of services provided by

other local authorities against their own. This will hopefully add an element of impartial and independent scrutiny, which will be necessary to reduce the variance in provision we currently see between local authorities in the provision of social care.

**Question 10: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?**

Yes.

There was a mixed response to this question. Some disagreed, with one explaining:

‘[I] disagree that the duty should be removed from the Health Board. Often a person is more in touch with their GP and other health services so this would be the first point of contact for them rather than their local authority.’

Others noted the importance of continuing health input:

‘As Health and Care integration moves forward, it would still place a responsibility on Health Boards, they should not be ruled out of the equation.’

‘The Strategy element of the Carers Information Strategy Groups may no longer be required with this proposed legislation, but the Group should continue to bring Health, Social Care and Third Sector together around the table to discuss how best to meet the needs of carers. Finances provided to this Group should also continue to support projects that have carers’ needs at heart, identify 'hidden' carers and organise carers’ events.’

## **Support to Carers (other than information and advice)**

**Question 11: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?**

Yes.

There was unanimous agreement from respondents that a duty should be introduced. One respondent noted:

‘The support for Carers should be an obligation that LA's have to undertake legally although the limits of this should be less regulated or defined. Under SDS it should be the Carer who decides what to allocate their funds towards.’

SDEF, along with other DPOs, however notes that no such statutory eligibility framework exists for ‘cared for’ people. Only national guidance on eligibility criteria exists. As a result, each local authority sets its own definition of these criteria resulting in significant inconsistency in the support and care packages available in different local authority areas.

This will aggravate the problem with the proposed situation whereby services provided to a carer as part of a Carer’s Support Plan will be free but 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 those receiving social care services.

There is a danger that a financial incentive will be created for local authorities to recognise support, such as short breaks, as being of benefit to the ‘cared for’ person rather than the carer. Doing so would mean that they could charge the recipient.

We, like other DPOs, are also concerned that as Carer Support Plans will be statutory, the provision of resources to meet them will take precedence over social care packages, which are discretionary.

**Question 12: Alternatively, should we retain the existing discretionary power to support carers and young carers?**

No.

**Question 13: Should we introduce a duty to provide short breaks?**

Respondents to this question were universally supportive of the provision of short breaks for carers. Comments included:

‘Regular breaks from the caring role can prevent a carer from reaching crisis point. Many care 24/7 for years and their own health and well-being is at risk if they do not get 'time out'. The cost of providing short breaks is nothing compared to the savings

that the carer provides for Health & Social Care. Regular short breaks can enable the carer to continue in the caring role for longer.”

‘Without such breaks carers break down and add cost.’

‘I do believe that short breaks should be supported, Carers have a tough time of it most days/weeks and respite would allow time to recharge batteries and also to reflect on the care they give’

SDEF notes, however, the conflict of the proposal with the principles of Self Directed Support. We recognise that the introduction of such a duty may be seen as a pragmatic solution to the choice by local authorities not to provide what they see as expensive breaks.

We, however, believe the root cause of such behaviour should be addressed, rather than the symptom. The provision of sufficient and appropriate care through a wider choice of support at the outset will help to reduce stress for both carers and ‘cared for’ people in the long-term.

## **Stages and Transitions**

**Question 14: Should we issue statutory guidance on the Carer’s Support Plan which will include guidance for those undertaking the Carer’s Support Plan on managing stages of caring? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child’s Plan through the stages of caring).**

Yes.

This proposal was strongly supported, with comments from respondents including:

‘Support should be provided to carers of all ages at different stages. More information and support is also required for those reaching retirement age and onwards.’

‘We are constantly talking about 'lifepans' which prevent the changes through a person’s life affecting the quality of life they should expect, why should carers not be accorded the same rights’

**Question 15: Should new carers’ legislation provide for young carers to have a Carer’s Support Plan if they seem likely to become**

**an adult carer? Any agreed support recorded in the Carer's Support Plan would be put in place after the young carer becomes a (young) adult carer.**

Yes.

Again, there was strong support from respondents, with comments including:

'It is important to prevent disruption to support for carers, therefore agree that under 18s should have the right to a Carer's Support Plan. In order to help them make that transition smoothly. Especially at a time when many 18 year olds are transitioning to further education or seeking employment.'

'For Young Carer, a carer's support plan could be considered at the age of 15 to take into account what the Young Carer planned to do at the age of 16 - continue in full-time education, start College, go into employment, take up an apprenticeship, or leave school with no employment prospects. Their needs could vary significantly depending on which path they chose.'

## **Carer Involvement**

**Question 16: 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?**

Yes.

There was unanimous agreement with this proposal from respondents. Comments included:

'Carers need to be involved in the planning of services for themselves and the cared for to achieve the best personal outcomes.'

'Who better than the Carer to understand the requirements of those whom they care for?'

Carers clearly have a unique understanding, from their perspective as a carer, of the needs of the person they care for. This is likely to be significantly better than professionals involved in the process.

SDEF agrees with other DPOs, however, that such involvement should not replace or undermine a 'cared for' person's views. The views of the carer may not be the same as their views and it cannot be assumed that the carer is speaking for them. Wherever possible, the 'cared for' person should be involved, in coproduction, in their own right.

**Question 17: Should we make provision for the involvement of carers' organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?**

Yes.

There was agreement with this proposal, with one respondent noting:

'Carer organisations are also helpful to consult with as they will be aware of any gaps in services and support from the people they are involved with.'

SDEF would expect carers' organisations to be part of a process of coproduction alongside DPOs.

**Question 18: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?**

Yes.

There was strong support for this proposal, with one respondent stating:

'Regardless of age, carers are the ones with the experience and knowledge on the person they are caring for and the support they need to help them.'

**Question 19: What are your views on making provision for young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers?**

Again, respondents were supportive of this proposal, with comments including:

'Very sensible, particularly for teenagers'

'We often ignore young people's views generally but in the case of carers they are probably the most relevant views we can take on board. Care plans should involve these views.'

## **Planning and Delivery**

**Question 20: 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?**

Yes.

There was agreement with this proposal, with comments including:

'Agree with proposals for a carer's strategy. This should include the support requirements for young carers to ensure they are getting the support they need.'

'Strategies should be developed and reviewed for ALL Carers, this at least focuses the minds of LA's'

**Question 21: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?**

Yes.

There was agreement with this proposal, with one respondent noting:

'I agree with this but extra resources will be required to ensure sufficient services are available for carers, particularly in remote and rural areas.'

## **Identification**

**Question 22: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?**

No. (SDEF is concerned that the confusing, negative, phrasing of this question suggests manipulation of responses to support the Scottish Government's view.)

The majority of SDEF's respondents were in favour of legislation, contradicting the proposal, with comments including:

'There is concern [that] if it is not a legal requirement that people will slip through the net. However this should be based on whether the carer themselves wish to be identified and recorded as a carer.'

'Legislation combined with monitoring by Health Boards would result in identifying more carers. The carers would then be made aware of support services available to them.'

'The rest of the process is formal, so the identification of carers should also be formal.'

**Question 23: Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?**

Yes.

**Question 24: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?**

SDEF is concerned that Health Boards are currently not monitoring compliance with core contractual elements of the GP contract. We would expect sanctions to be imposed by Health Boards in such circumstances.

**Carer and Cared-for Person(s) in Different Local Authority Areas**

**Question 25: What are the views of respondents on the lead local authority for undertaking the Carer's Support Plan and agreeing**

**support to the carer where the carer lives in a different local authority area to the cared-for person(s)?**

Almost all respondents to SDEF's consultation believed it should be the service user's local authority that was responsible.

**Question 26: What are the views of respondents on which local authority should cover the costs of support to the carer in these circumstances?**

Almost all respondents believed it should be the service user's local authority.

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

No.

Given the current discussions about the break up of COSLA, and the wholesale failure of their non-residential care charging guidance to deliver a fair system, we do not agree with this proposal.

We believe that the poor practice seen in relation to the portability of care requires a stronger response than guidance. Regulation is required and this should address the needs of both carers and 'cared for' people.