Inclusion Scotland

Inclusion Scotland is a national network of disabled people’s 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. Inclusion Scotland is part of the disabled people’s Independent Living Movement.

In a response to the Consultation on the Draft Carers Bill last year, National Disabled People’s Organisations made the following joint statement:

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 carers’ 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

This submission examines the extent to which the published Bill meets the aspirations of disabled people as set out in this statement.

1 Do you support the Bill?

1.1 As stated above, DPOs welcome and support the general principles of the Carers (Scotland) Bill. 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.

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1 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”. This definition has been endorsed by the Scottish Government, NHS Scotland and COSLA in “Our Shared Vision of Independent Living In Scotland” http://www.scotland.gov.uk/Publications/2013/04/8699

2 Inclusion Scotland, Independent Living in Scotland project (ILIS) and Self-Directed Support Scotland (SDSS)
people. To face the significant challenges ahead, the progression of social care and support in Scotland needs to be co-produced with disabled people and carers.

2 What do you feel would be the benefits of the provisions set out in the Bill?

2.1 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. 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.

2.2 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.

2.3 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, it can also be the case that the partner or close relative takes on the functions of a carer because there is been no adequate or affordable social care package available. Unpaid care in this context becomes a compulsion out of necessity, not a choice.

2.4 It can be difficult to detect when the balance between choosing to have support from a partner or close relative who willingly provides some support switches to reliance on them as a full-time carer changes. The impact this change has on the personal relationship between the carer and the “cared for” person can be profound. The carer/cared for relationship has to be freely chosen by both parties, if it is not to be to the detriment of both. Improving support for informal carers must not become seen as an alternative to adequate investment in social care services/packages provided directly to the “cared for” person.

2.5 Inclusion Scotland has frequently highlighted the crisis in social care which has seen the focus moved to meeting only critical and substantial need. This leaves many people who may need only a little bit of support to stay in their own homes, for example some help to get dressed, without any support.

2.6 In addition to managing demand through higher criteria for people to receive social care, local authorities have increased the amount disabled people are charged to receive those services. Scottish Government figures show that over the last three years, care charges throughout
Scotland have risen on average by 12%. Increases by some local authorities have been far more than that.

2.7 This leads to an increased reliance on unpaid carers, mostly women, who may have no choice but to give up work.

3 How do you feel the Bill could be amended or strengthened?

3.1 Inclusion Scotland supports a human rights based approach to public policy, and would welcome the inclusion of underlying principles of choice, dignity and control in the Bill, 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).

3.2 We agree with the “Carers (Scotland) Bill – Third Sector position statement” prepared by seven national carers organisations (NCOs) that the meaning of “personal outcomes” in Section 4(1) is too narrowly defined referring only to enabling the carer to provide or continue to provide care. Personal outcomes should also refer to the carer’s right to a life outside of caring, or indeed not to provide care at all. Inclusion Scotland also believes that the personal outcomes of the “cared for” person also need to be taken into account, in particular the right to independent living and to freedom, choice, dignity and control.

3.3 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.

3.4 DPOs have long argued for national standards in criteria, eligibility and assessment for social care, for disabled people and for carers, and support the NCO Statement on this issue. National criteria would ensure a fair and equitable application of social care and support across Scotland.

3.5 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.

3.6 Whilst we recognise that there may be good reasons to provide support in different ways to meet local needs and circumstances, we can see no logical reason why the eligibility criteria for support should vary from area to area. We therefore believe the Bill should be amended to require the Scottish Government to set national eligibility criteria for both carers and the “cared for person”.
3.7 Article 19 of the United Nations Charter on the Rights of Disabled People (UNCRPD)\(^3\) established that disabled people have a fundamental right to independent living and inclusion in the community, including access to a range of in-home, residential and other community support services. DPOs believe that charging for social care goes against the human rights of disabled people.

3.8 Inclusion Scotland notes that s24 of the Bill extends the power of local authorities to charge for support to carers. We also note that the paragraph 98 of the Financial Memorandum states that “it is fully expected that regulations will be made to waive charges for support to carers”. This seems an illogical approach. Would it not be better to state in the primary legislation that support for carers under the Bill will not be charged?

3.9 We support services to carers should be provided for free, but believe that this principle should also apply to all social care service users. There is an inconsistency in the proposal that services provided to a carer as part of a carer’s support plan will be free, but those supplied to the “cared for person” as part of a social care package may be charged for.

3.10 Indeed, the Bill recognises that the carer’s needs could be met (wholly or partly) by the provision of services for the cared for person. This could 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. Waiving charges to carers only, could result in a (perverse) incentive for families to choose unpaid care where they may have otherwise chosen to have support provided direct to the cared for person.

3.11 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).

3.12 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.

3.13 We are concerned about the term “cared for persons” which can imply that the person receiving care is a passive recipient of that care, rather than an equal partner, with the carer and the statutory authorities. We note that there is an inconsistency of language between Health and

\(^3\) [http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19)
Social Care Integration (service users) Self-directed Support (supported persons) and this Bill (cared for persons) which could lead to confusion.

4 Is there anything that you would add to the Bill?

4.1 In its consultation on the draft Carers legislation last year, the Scottish Government recognised that “there are issues to be addressed about the portability of assessment, primarily for service users”. Despite the consultation confirming that this is a “significant issue”, no proposals have been brought forward to address this issue beyond “the Scottish Government and COSLA working together to improve portability of assessment”.

4.2 Service users and our member organisations tell us that portability is a substantive issue in the continuity of care and support across Scotland.

4.3 Continuity of 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;
- 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 how long it might take; and
- offer no protection of levels of support or type of service

4.4 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.

4.5 Given experience to date of the extremely slow progress on social care charging, DPOs believe that the Scottish Government and COSLA working in coproduction with DPOs and Carers organisations is likely to be a more effective way to develop the legislative framework to address the issue of portability.

4.6 There does not appear to be any provision in the Bill for a carer to challenge any decisions of local authorities in respect of any aspect of the Adult Care Support Plan or Young Carer’s Statement.

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DPOs have consistently called for an independent and impartial social work complaints system to allow individuals to challenge local authority decisions regarding their eligibility for social work services, including self-directed support, social care packages, health and social care integration, and care charges.

Despite assurances given to the Health and Sport Committee in October 2013 by the then Cabinet Secretary during the passage of the Public Bodies (Joint Working) Act, that proposals for a new social work complaints system would be published by the end of that year (2013), there has been no progress on this. DPOs remain ready and willing to work with the Scottish Government and COSLA to coproduce a social work complaints system.

5 Conclusion

Inclusion Scotland do not object in principle to establishing a statutory duty to support carers, but there is a need to ensure that this is consistent with the support provided to disabled people. Disabled people need to be equal partners in coproducing their own care plans and carer support plans to ensure that the personal outcomes for both the carer and the “cared for person” are supported.

However, the policy objectives of the Carers Bill will not be met whilst there is a funding crisis for social care that leaves many disabled people unable to access the services they need to support independent living. This leaves families, cared for people and many carers with no real choice in whether or not they are willing or able to accept or provide unpaid care or the amount of that care.

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