Carers (Scotland) Bill

Children in Scotland

Children in Scotland is the national network organisation for the children’s sector in Scotland. We have over 440 members in the public, voluntary, community and independent sectors. We are aware that several of our member and partner organisations have responded at length and in detail to the call for evidence and while we broadly endorse and support their responses, we would not propose to reiterate many of the points made.

We welcome the opportunity to respond to the Committee’s call for views on the Carers (Scotland) Bill. Unpaid carers make a significant contribution to our society and we welcome the Scottish Government’s decision to introduce legislation to deliver new rights and entitlements to improve outcomes for all carers in Scotland. We commend the Committee’s efforts to gather directly the views of those with caring responsibilities. Children in Scotland has since 2012, worked with a large group of parent carers of disabled children through the Parent Participation Project, a Scottish Government funded project in partnership with for Scotland’s Disabled Children (fSDC), which aims to enable parents of disabled children to have more influence on policy matters that affect them and their children.

We converted the questions from the Committee’s ‘Call for views from people with caring responsibilities’ into an online survey and shared this across our network of parent carers. Parents were able to indicate if they supported or were against these aspects of the Bill and were able to add further comments if they wished. From experience we have found online surveys to be the most time-efficient method for busy parents with limited free time to be able to have a voice and share their views in these types of consultations. In total, 58 parent carers responded to our survey.

Responses from parent carers

1. What do you think about the proposals to offer adult carers a support plan and to offer young carers a young carer’s statement?
83% of respondents felt that these proposals were a good idea, 16% of respondents were unsure, and one parent carer did not support these proposals.

Some of the parents who added further comments were unsure about how the proposed support plans would actually impact on their own situations:

“Not sure what this would add to my life as a carer, if it would help access support then it’s positive.”

“A care plan in itself does not mean we will get the help we need.”

Parents also raised concerns around the availability of resources to fully implement these support plans:
“Good idea if the resources are made available to carry them out. For example, I’ve been awarded respite hours but have been unable to find carer for the past 2yrs.”

“That seems like additional paperwork and a waste of time and resources. More thought should go into how to support carers, e.g. better respite. A written plan isn’t necessary.”

Parents also expressed a desire for further clarity and information:

“…understanding what should be available…..these [support plans] need to be available to read, be explained etc., to be anywhere near effective.”

In early 2014, Children in Scotland conducted a survey of more than 250 parent carers as part of the aforementioned Parent Participation Project. 79% of respondents to our survey told us that being a parent of a disabled child has had a negative impact on their own health and wellbeing. 65% of respondents said they had never been offered or received any support for their own needs, such as counselling or a support group.

2. What do you think about the proposal that councils must consider, in particular, whether the support they provide should take the form of a break from caring for those with caring responsibilities?
84% of respondents felt that this proposal was a good idea, 9% of respondents were unsure, and 7% of respondents did not support this proposal.

Some of the parents who added further comments had concerns about local authorities making decisions around eligibility for support:

“The decision of what support is provided should be decided without input from Local Council. If people are entitled to support by default they should receive it without any discussion from council.”

“Again it will only be relevant if the councils decide they agree, and does not force councils to give a break.”

Respondents also emphasised the importance of breaks from caring to their own health and wellbeing:

“I think it MUST include a break from caring. That's often the number one thing carers need.”

“If your child gets respite care it then gives the full time carer time to themselves or spend quality time with other family members (children).”

One parent also challenged traditional interpretations of ‘breaks’:

“…A break doesn't just mean overnights. It could be coffee with a friend, a spa day or anything else that makes sense to the person.”
In our 2014 survey we asked two specific questions around breaks from caring responsibilities. 65% of respondents said they did not feel like they were able to access the support they need to have occasional breaks from caring. 92% of respondents said they would be in favour of the introduction of a duty to provide short breaks (as is the case in England and Wales).

3. What do you think about local councils being given the responsibility to establish information and advice services for carers?
60% of respondents felt that this proposal was a good idea, 23% of respondents were unsure, and 17% of respondents did not support this proposal.

Of those parents who provided further comments, the majority highlighted existing information and advice services, e.g. carers centres, and raised concerns over the duplication of these provisions:

“I think it’s often better if these things are subcontracted. There are lots of existing resources with loads of experience that could be utilised rather than duplicating services and wasting money.”

“As long as they work with the organisations already in place.”

“We already have information through a number of various charities and advice and information services, some council funded.”

4. What do you think about councils setting local criteria for those who would be eligible for support?
39% of respondents felt that this proposal was a good idea, 31% of respondents were unsure, and 29% of respondents did not support this proposal.

Of those parents who provided further comments, the majority raised concerns over equity of access to services under locally determined eligibility criteria:

“Much better if this was done centrally, then everyone would be treated the same.”

“It needs to be consistent across the board and not a postcode lottery.”

“It’s important that access to service has some clear criteria so carers know if they are eligible and so everyone gets treated the same.”

Some respondents also added that carers should be involved in the setting of criteria and further planning:

“Depends what the criteria is going to be and who is being considered when the initial criteria is drawn up. Parents should be involved in the decision making process throughout the whole consultation.”
5. Is there anything you think should be changed or added to the Bill?

Some respondents highlighted issues around anticipatory care planning, including transitions from child to adult services:

“[The Bill] should take into account the impact having a disabled child has on all of the family. Also when the child becomes of age to keep support going.”

“My son has a degenerative, terminal condition… It is inevitable that my wife or I will have to give up work at some point to provide the full time care he will need. It can only be good that there is a system in place so people like us are known about, and can be helped when the time comes.”

Respondents also emphasised the need for consistent support at an early stage to avoid parent carers reaching “crisis point”:

“Respite for parents must be regular… to prevent full-time carers from "collapsing" with the constant commitment they need to give to their children and developing their own health problems as a result.”

Concluding points from Children in Scotland

While we broadly support the introduction of the Carers (Scotland) Bill and its aim to extend and enhance the rights of both adult and young carers in Scotland, our survey of parent carers and our discussions with our member and partner organisations have highlighted several areas which require further attention.

Briefly summarised below are the additions, or areas that need strengthened, that we believe would improve this legislation to ensure the best possible outcomes for both young and adult carers, echoing the views of our third sector colleagues and the parent carers we consulted with above.

National eligibility criteria

The Bill places a duty on local authorities to provide support for carers who meet local eligibility criteria. Many of the parent carers we consulted with were explicit in their response that they believe eligibility criteria should be defined and decided at a national level. They feel that this is the only way to avoid a “postcode lottery” and to ensure that carers have equity of access to rights and entitlements across Scotland.

We understand that each local authority has differences in needs and circumstances and having flexibility in setting eligibility criteria is important e.g. variances between the service needs of carers in rural and urban area. In order to minimise the risk of inconsistencies area to area, it is important that local authorities are supported with information and resources from a national level in determining their own eligibility criteria. This also takes account of lessons learned from the current delivery of the Self-Directed Support legislation for children’s services.

There is wide support from both carers and third sector organisations for a framework of national eligibility criteria for support, which would ensure a fair
and equitable application of social care and support across Scotland. 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” with appropriate levels of flexibility, information and resource for local authorities to implement.

**Involvement of carers and ‘cared for persons’**
We welcome the duty on Local Authorities and Health Boards to involve both adult and young carers and carers organisations in the planning, shaping and delivery of services. Parent carers frequently highlighted throughout the survey that they would want to be involved in both further consultations about the Bill and in the future delivery of services. Carers often have expert and informed knowledge around the needs of the person they care for and local authorities should draw on this as an effective resource.

Provision should also be made for the cared for person to be involved and for their views to be taken seriously, including young children and those with complex needs or communication difficulties. They will have experiences and opinions that can help shape effective services, and it is important that efforts are made to ensure that this valuable information is adequately captured and appropriately utilised. Support packages and carer support plans should be developed through co-production with the carer, the cared for person and statutory services.

**Provision of information and advice**
Whilst we welcome a duty on local authorities to provide information and advice to carers, we believe this would be best achieved by further resourcing the many existing services that work with carers and young carers across Scotland. These services are often well-established and well-known in their local areas and there should be further considerations as to how the local authority can support these organisations to manage an increased demand on their service.

Many of the parent carers we consulted with echoed these concerns over the duplication of effort in creating “new” services. We believe new services should be established only if there is an identified gap.

Through Enquire, the national advisory helpline for additional support for learning, we have also heard from parents of the need for national level information and one single port of call for this information. This is recognised in the current Education (Scotland) Bill and Children in Scotland is working with Scottish Government to look at how this can be delivered. It is recognised amongst parent carers that finding their way through a raft of information sources can be a challenge and that anything that streamlines this and makes that exercise easier would be welcomed.

**Integration with the Children and Young People (Scotland) Act and other legislation**
In order to protect, respect and fulfill the rights of young carers, the Carers Bill must be consistent with, and complementary to, existing duties to promote the
rights and wellbeing of children and young people, as detailed in the Children and Young People (Scotland) Act.

We would also support the calls made by Inclusion Scotland to include the 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 in the Social Care (Self-directed Support) (Scotland) Act 2013.

This Bill should also take into consideration provisions under the Education (Additional Support for Learning) (Scotland) Act 2004 and forthcoming amendments in the Education (Scotland) Bill.

Child Rights Impact Assessment (CRIA)
We endorse the responses of Together (Scottish Alliance for Children’s Rights) and Children 1st in calling for a CRIA to be undertaken to ensure that this Bill is fully assessed in terms of its impact on the rights of children.

Impact on the third sector and resourcing
We have concerns that the impact on carers’ centres and other third sector organisations has not been fully recognised within the Bill. Organisations that support carers could experience greater demand for their services if there are more carers being identified. Moreover, the additional duties on local authorities to provide carers with information and advice may too result in an increased demand on third sector organisations. Finally, the Bill’s requirement for local authorities to involve and consult with carers will also impact on the third sector as carers will require support in order for them to be able to participate meaningfully in service planning and delivery, and carers organisations will require dedicated resources to deliver this support. Resourcing to improve third sector capacity will be essential in order for carers to be adequately identified and supported.

There are direct links with Part 3 of the current Education (Scotland) Bill, particularly in relation to seeking the views of young children and young people, extending the rights of children and young people and the provision of information and support that should be considered alongside these recommendations also.

Importantly, we note that the sector is experiencing a range of new legislation and it is vitally important that connections are made at a national level across these different pieces of legislation to minimize the risk of duplication and conflict and the impact that may have on delivery and ultimately outcomes for children, young people and their families.

Children in Scotland