

Aberlour's written stage 1 evidence to the Health and Sport committee of the Scottish Parliament in respect of the Carers Scotland Bill

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Working in over 40 locations across Scotland, we offer a diverse portfolio of services to vulnerable children and families facing adversity or a range of vulnerabilities. As such there are three specific groups of carers that we work with in this regard:

1: Parent carers of children with profound and complex physical and learning disabilities: We have both short break respite and long term residential care services for families affected by disability.

2: Siblings of children with profound disabilities who provide caring support in the home: Many of the siblings of children with disabilities with whom we work have to grow up far earlier, and take on more responsibilities in the home than their peers. We have designed special packages of support for these siblings that recognise the very special role they play.

3: Children affected by parental substance use who provide a caring role for siblings or parents themselves: We have decades of experience working with families affected by parental substance use. We work in a holistic way to build both parental capacity and resilience and attachment in the children we work with.

In the lead up to the instruction of this bill and as part of our response to the pre-legislation consultation, we undertook a range of focus groups with parent carers of children with whom we work. This, along with input from young carers and sibling carers has helped to inform our response.

We have kept our remarks brief and to reflect the interest of our organisation in this regard. It can be inferred that we are broadly content with the sections not referenced in our response.

Top lines:

- We want to see a child rights impact assessment conducted on the Bill
- We think that responsible authority should have a duty to communicate the existence of support plans for carers to both adult and child carers proactively
- Qualification for support should be triggered by impact on the carer of the care they provide and not by the existence of a medical diagnosis
- We need to define what is meant by wellbeing in the context of adult carers
- Adult carers plans and young carers statements should signpost to all other avenues of statutory support including benefits etc. and raise awareness of SDS.
- There must be an appeal mechanism for carers should the authority not identify any support needs
- Young carers statements should be renamed 'young carers support packages'

- Young carers should have a statutory right to access the services of a trained advocate when being assessed for a support package or appealing the decision of the authority.
- Eligibility criteria for support should be set on a national basis not a local basis to prevent inconsistency and the possibility that authorities may seek to reduce the number of people who qualify for financial reasons
- The proposed duty on authorities to “consider” respite as a possible support to a carer with identified support need is not strong enough. Respite should be the norm except in exceptional circumstances.

Children’s rights impact assessment:

We would like to indicate our support for calls from Together- The Scottish alliance for Children’s Rights for the Government to commission a child rights impact assessment on the Bill before it enters stage 2 of the Parliamentary process.

Part 2: Chapter 1 Adult Carer’s support plans:

Duty to prepare an adult carer support plan: When we asked our focus groups, most didn’t even know what a carer’s assessment was in the first place. Indicating that they had never been offered one or if one had been undertaken it had not been done so in a sufficiently formal way to have registered. This underscores the inconsistent nature under which carers assessments are currently undertaken and those who were aware of it said there had never been a great deal done to promote one to them.

Nevertheless, following discussion, those parents present felt that the shift in name was positive as it suggested a presumption that support would follow once an assessment was undertaken. As such we welcome the introduction of a statutory adult carers support plan.

Giving adult carers the right to ask for a support plan to be prepared:

The pre-legislation consultation asked whether respondents would support the idea of a statutory right for carers to ask for a support plan. This was widely welcomed by the families we consulted. To this end we warmly welcome the provision within Part 2, Section 6 (4) which stipulates that an adult support plan must be prepared if a person presents to the responsible authority and asks for one.

Communicating information about support plans to adult carers:

Our experience tells us that many carers in Scotland go unidentified, largely unaware of support that might be available to them and as such unlikely to ask for help. One parent carer whose daughter has severe and complex disabilities revealed that it had been 2.5 years before they realised that as a family they were entitled to any kind of financial assistance, such as the DLA or the carers allowance and then only after a chance conversation with another parent.

To remedy this we feel there should be a duty on ministers and responsible authorities to communicate the existence of carers support plans and the types of circumstances in which it might apply. It would be beneficial we believe, for this to appear on the face of the Bill.

Adult carers: Identification of outcomes and needs for support

This section lays out the means by which Scottish Ministers will determine how personal outcomes and needs are to be identified. The Ministerial orders which underpin this section will be critical to how assessments of need are undertaken. This presents a significant opportunity to bring greater consistency in assessing the needs of Scotland's carers.

At present, support for carers is inconsistent across the country. The carers we support expressed general dissatisfaction at the level of support that had been offered to them and this was also their view of a general lack of information.

Expanding qualification for support:

It is critical that the specifics of the Ministerial orders underpinning this section recognise the why carers need support in the first place. Our parents felt that whether they qualified for support was currently tied to certain triggers, such as a medical diagnosis. This means that many are excluded from support particularly when there was an absence of a confirmed diagnosis for their child, as is often the case in the early years of a condition, then there was potential for carers not to qualify when there was, nevertheless a real need for support.

The language in the Bill around qualification seems to suggest a welcome shift. We feel that the Bill could be more explicit in stating that the trigger for an adult carers support plan should be an assessment of key lifestyle implications of their caring responsibilities and impact on wellbeing and not on the diagnosis of a child's condition.

Content of an adult carers support plan:

Section 6 (1) (a) part ii) states that the support plan must contain information about the impact of caring on the adult carer's wellbeing and day to day life.

Quantifying wellbeing:

We welcome this but are keen to ascertain the indicators to be attached to the definition of Wellbeing. Children have wellbeing defined in primary legislation under the SHANARRI wellbeing indicators. These are particularly helpful in building consistency around things like assessment and reporting. We would suggest that adult indicators of wellbeing be included as a schedule to this Bill.

Signposting to other avenues of statutory assistance and raising awareness of SDS:

The Bill proscribes a range of pieces of information to be included in a support plan; these cover a range of things including the support services available to the carer in the area covered by the responsible authority. We are supportive of the inclusion of those items listed but feel the plan should also signpost adult carers to other avenues of statutory support. As described above, entitlement to state benefits is not universally understood by adult carers. It would be helpful for the support plan to direct adult carers to any state provided benefits to which they are entitled. Similarly, the contents of the plan should reference the choices available to the adult carer and their family through self-directed support, under the terms of the Social Care (Scotland) Act.

Need for an appeal mechanism when no needs for support are identified by responsible authority:

Whilst the Bill stipulates that there must be steps to review each plan as part of the contents of the Plan, the Bill does not currently offer statutory grounds for appeal should a person present to a responsible authority, ask for a support plan and find that the authority identifies no needs for support in that person's situation. It is essential for an appeals mechanism to be established on the face of the Bill.

Chapter 2: Young carers Statements:

Nomenclature: We understand the difference in nomenclature of the young carer's statement from the adult carers support plan is designed to remove any confusion or false interrelationship with the single child's plan. We are unconvinced however, that the term 'young carer's statement' is sufficient to convey the level of support a young carer can hope to receive from the responsible authority. We would suggest something more indicative of the improved regime the government hopes to foster in this: '**young carer's support package**' would better reflect what young carers could hope to receive and make them more likely to come forward for assessment.

Young carers: Identification of outcomes and needs for support

Need for an appeal mechanism:

As with adult carers, there must be an appeal mechanism by which a young carer who presents to a responsible authority, asks for their support needs to be identified and the authority determines there are no identifiable support needs. This needs to be on the face of the Bill.

Independent advocacy for young carers while support needs are identified:

Given the particular stress and vulnerability experienced by young carers, which in turn may have an impact on their ability to adequately represent their situation to a responsible authority, some access to advocacy is necessary in the process of identifying needs for support. To this end we would like to see a statutory right to the services of a trained independent advocate, during assessment of their needs for support on the face of the Bill. Similarly such services should be available to them during an appeal should the responsible authority fail to identify any needs for support.

13: Content of a young carer's statement:

Signposting to other avenues of statutory support:

As with the adult carer support plan, the young carer's statement should contain direction to any relevant state assistance to which that young person may be entitled.

Appeals information

The young carer's statement should also contain details on how a young person can appeal the conclusion of the responsible authority and how they can access the services of an independent advocate to help them in this regard.

Part 3: Provision of support to carers

Chapter 1: Duty to set local eligibility criteria:

Whilst the Bill does set out the need for national eligibility criteria to be proscribed by Scottish Ministers, to steer the production of local eligibility criteria produced by Local authorities, we feel that eligibility criteria should be set by Scottish ministers alone and not each local authority.

One of the biggest problems identified by the carers we consulted as part of our response to the pre-legislation consultation was inconsistency of provision. Local authorities, facing funding shortfalls, may be tempted to set eligibility criteria at a higher level in order to reduce carer demands on services.

Furthermore, having a localised approach to eligibility criteria could also see families actively moving to areas with more permissive eligibility criteria.

Naturally Scottish Ministers, when producing eligibility criteria, should consider aspects of geography, deprivation, urbanity and rurality to ensure that eligibility criteria reflects the various challenges experienced by all carers across the country.

Chapter 2: Duty to provide support for carers.

23: provision of support to carers: breaks from Caring

The question in the pre-legislation consultation which attracted unanimity amongst the carers we spoke to was about whether there should be a duty on local authorities to provide respite to carers.

Need for a duty on local authorities to provide respite to carers as the norm

Section 23 (1) states that a local authority must “**consider**” whether the support to be provided should take the form of or include a break from caring. We would argue that this makes determination over respite subjective on the part of the local authority and makes no real difference to arrangements as they are now, where it is in the gift of the authority to determine whether a carer merits respite.

This section needs to be significantly strengthened. We would suggest that the Bill impose a duty on the Local Authority to provide respite to carers with identified support needs and that this duty should no longer apply only in exceptional circumstances defined by Scottish Ministers.

Conclusion

We warmly welcome the introduction of this Bill and will work to support the Scottish Government in its development in any way that we can.