Carers (Scotland) Bill

Alzheimer Scotland

Introduction

Alzheimer Scotland is Scotland’s leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to contribute to the Health and Sport Committee’s call for evidence as part of its scrutiny of the Carers Bill. Alzheimer Scotland supports the National Dementia Carers Action Network (NDCAN) and our response has been informed by that group, as well as by the experience and knowledge people who use our services, their families and our membership.

We believe the committee should consider longer timescales for future calls for evidence. This legislation is extremely complex and will have a profound impact on the lives of carers across Scotland. Presently, it is challenging to capture the knowledge and experiences of carers for people with dementia and our professional colleagues, in the timescales given and it would be helpful if the committee extended its submission period. In doing so, we would be able to engage with our membership in way which is both meaningful and accessible to them.

Do you support the Bill?

Alzheimer Scotland strongly welcomes the principles of the Bill and its intention to ensure that the rights and needs of carers are fully recognised and met. Given the importance of carers in supporting people with health and social care needs to stay within their communities, we believe this Bill is a welcome development. However, there are elements within the Bill with which we have some concerns, including a number of areas we addressed in our response to the pre-legislative consultation.

Specifically, we welcome that the Carers Bill:

- Replaces the Carer’s Assessments with Adult Carer Support Plans.
- Will place a duty on local authorities to meet the needs and respect the rights of people in a caregiving role.
- Establishes provisions for the establishment of information and advice services for carers in each local authority, including a short breaks services statement.
• Requires local authorities, in determining the needs of carers, to give consideration to whether support should take the form of, or include, a break from caring.

• Requires local authorities to prepare local carer strategies for their areas.

• Establishes the principle of involvement, requiring the inclusion of carers in all services delivered by local authorities and health boards for carers and cared-for persons.

In particular, Alzheimer Scotland is pleased that local authorities will be required to take into account the care provided by carers when conducting an assessment of the cared-for person and must give consideration to an Adult Carer Support Plan (ACSP) where one is in place and that in all cases, the local eligibility criteria, we welcome that the local authority must take account of the care provided and ascertain what level of support the carer is ‘able and willing’ to provide.

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

Alzheimer Scotland believes that the introduction of the Adult Carer Support Plan (ACSP) in place of the Carer’s Assessment will help to ensure that carers will more easily have their needs identified and met, ensuring that they are supported in their caregiving role, particularly by extending the ability of carers to request an assessment and by removing the ‘regular and substantial’ condition for support.

Furthermore, we believe that the inclusion of a requirement for ACSPs to include timescales or specified circumstances under which the plans should be reviewed is welcome, particularly for people providing a caregiving role for a person with a progressive condition such as dementia whose needs for support will change considerably over time.

However, whilst the provisions contained within the Bill have the potential to strengthen the rights of carers, recognising their crucial role in providing support for people with health and social care needs, the benefits for carers and cared-for persons will be determined by the implementation of the legislation at the local level.

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

Alzheimer Scotland believes that the Bill would benefit from amendments in certain areas (detailed below). However, we note that many sections of the Bill are written in such a way as to allow Scottish Ministers to make regulations or issue statutory guidance on the way in which local authorities should provide support to carers. Therefore, much of our submission may not refer to amendments which should be made to face of the Bill itself, rather what must be set out in accompanying regulations or statutory guidance.
Whilst the Bill itself is an important step in recognising and supporting carers, one of the key factors which will determine its success will be how resources are allocated and used within localities. We know from the experiences carers have shared that there are frequent cases where needs are identified (either for the carer or for the cared-for person) which go unmet due to a lack of resources being available within the locality. Carers have expressed concern that without further resources being made available, they do not believe that their needs will actually be met and that the legislation will not have the desired effect.

**Adult Carer Support Plans**

Alzheimer Scotland is concerned about the provisions which will allow Local Authorities to specify timescales for completing an ASCP for an identified carer within their own Local Carer Strategy. We believe that this may lead to considerable variation in waiting times across the country. In addition to the potential variation as a result of local eligibility criteria (addressed below), we are extremely concerned that there will be no consistency of provision or support for carers across Scotland, and no improvement in their outcomes, undermining the purpose of this legislation. It is therefore crucial that, in partnership with local authorities, carer organisations and other relevant stakeholders establish a national timescale in which carers will be assessed for a support plan.

We further believe that there must be a third path available for accessing an assessment for a support plan, with third and independent sector organisations with whom the carer (or cared-for person) may be involved, being able (with the consent of the carer) to make a referral for a Carer’s Support Plan.

Alzheimer Scotland notes that emergency, anticipatory and future planning will be considered on an individual basis and will be covered in regulations about other information that an Adult Carer Support Plan must contain.

Related to this point is the absence within the legislation of carer involvement in hospital admission and discharge procedures, which would place a responsibility on health boards to inform and involve carers in hospital admission and discharge procedures.

We are aware that the Scottish Government intends to issue guidance around Adult Carer Support Plans, which will include information on the different stages of caring and the need for a review to address periods of transition.

Carers have told us that these transition points can be the most stressful and difficult periods of their caregiving role. It will therefore be essential that as part of the legislative process around this Bill, the full range of expertise and experience of carers, professionals and stakeholders are taken into consideration to make sure that the final legislation and accompanying guidance ensure that the right support is provided for carers both as part of their ACSPs and during the transition periods.
Eligibility Criteria

Carers are concerned about what locally set eligibility will mean in practice for them and how it may affect their ability to access services. Whilst we appreciate that there is a need for flexibility within the legislation so that local authorities provide services which are responsive and meet the needs of carers within their locality, there is likely to be considerable variation in criteria between local authorities. This will likely lead to inequities in provision across Scotland and create a lack of clarity for carers, directly contrary to the Policy Memorandum’s description of ‘a Scotland-wide approach’.

Whilst we appreciate that within the Bill there is provision for Scottish Ministers to set out national eligibility criteria if they ‘come to the view that the local eligibility criteria are not working in the intended way’, we do not believe that it is desirable that this decision should be taken reactively. Doing so risks leaving many carers and cared-for persons in extremely difficult circumstances unnecessarily. Carers are often the primary source of support for the cared-for person, frequently putting in long hours, while balancing other responsibilities such as work and other family commitments over long periods of time with little or no support. Over time this can have an impact on the physical and mental wellbeing of carers. As a result many carers are in crisis before they or those they care for receive formal support. Therefore eligibility criteria must place an emphasis on prevention. Smaller less costly carers’ support at the right time may be a better use of resources which may prevent many of the expensive crisis interventions. However, this will only be effective if this approach is taken in all localities across Scotland.

The Bill should therefore be amended to ensure that core eligibility criteria are set nationally either in the face of the Bill or through regulations in consultation with local authorities, carer groups and other relevant stakeholders.

Responsible Local Authority

Whilst we welcome the removal of the requirement that the cared-for person must be someone to whom a community care service is provided, Alzheimer Scotland is concerned about the definition of ‘responsible local authority’ (i.e. the body obligated to ensure that the needs of carers are being met) set out in chapter 1, Item 6 (5) as: ‘The local authority for the area in which the adult carer resides’.

Alzheimer Scotland does not believe that the local authority in which the caregiver resides should de-facto be the ‘responsible local authority’. As indicated in the pre-legislative consultation, we takes the view, informed by members of our National Dementia Carers Action Network (NDCAN) and other carers, that the lead local authority in these circumstances should be the one where the cared-for person lives; the support the carer receives will have a direct impact on the amount and type of support that is required by the cared-for person.

In addition to this, carers tell us that they believe that as the Bill stands, they may be overlooked for assessment in instances where they reside in a
different local authority from that of the cared-for person. In this situation, the relevant services in the local authority of the adult carer are unaware of the adult carer (as the individual may otherwise have no reason to be involved with or in contact with services), their needs or the care-giving role they provide. At present, it is the responsibility of the local authority of the cared-for person to carry out an assessment and accordingly provide self-directed support or other services as appropriate.

We therefore believe that the legislation must be amended to define the ‘responsible local authority’ as ‘the area/local authority in which the cared-for person resides’.

We further believe that the Bill as introduced does not make adequate provision for carers who may care for more than one person, across multiple local authority areas. As a result, it is likely that support for a carer may not be suitably delivered solely on the basis of the locality in which they reside. It is therefore imperative that statutory guidance, applying to all local authorities, should make provision for this and should include:

1. Cost recovery where a local authority other than the lead authority is providing an element or elements of the support identified as necessary in the Adult Carer’s Support Plan.

2. A process for agreeing who should provide each element of the support identified in the Adult Carer’s Support Plan, particularly where it may not be the ‘responsible local authority’.

Alzheimer Scotland would also welcome inclusion over the need for Adult Carer Support Plans (ACSPs) to contain common elements across each local authority in order to ensure that they are portable and cause minimum disruption to a carer moving between local authority areas. This was a key element of the pre-legislative consultation but is not included within the Bill as introduced. Ideally, in light of the integration of health and social care services and the establishment of health and social care partnerships, the ACSPs should be recognised in all health and social care settings.

Involvement

Alzheimer Scotland warmly welcomes the duty on local authorities to develop and publish local carer strategies and to involve carers in the development and review of these strategies (as well as in the development, delivery and review of services. We believe that the regulations and/or statutory guidance must ensure local authorities provide accessible formats to carers which must take into consideration the different circumstances and additional needs that carers may have. This includes the format of engagement (for example, written consultations may require large text versions or easy read versions) and consideration of additional daycare if carers are asked to attend in person (through focus groups or interviews). The accompanying statutory guidance or regulations should require local authorities to give due consideration to these additional barriers to involvement and should further require them to work with
stakeholders and partners to find ways to support meaningful involvement of carers.

Involvement is crucial to supporting the implementation of Human Rights legislation, in particular, the PANEL approach requiring active participation in decisions that affect people’s human rights. This human rights based approach should be explicit in the primary legislation, aligning with and strengthening other Scottish legislation around health and care including the Self Directed Support Act and the Public Bodies (Joint Working) Act. Involvement must be meaningful, so health and social care professionals require appropriate training to make sure that they are able to work in this way.

**Short Breaks**

Alzheimer Scotland supports the principle behind a specific duty on local authorities to provide short breaks and the creation of such a provision is support by carers. We remain concerned that the use of the term ‘short break’ is not adequately clear and may be open to different interpretations between professionals, carers and organisations as to what a ‘short break’ constitutes. Our submission to the pre-legislative consultation suggested that the duty could be altered slightly to provide flexibility for the support to be personalised to reflect the needs and the wishes of carers. For example, the carer and cared-for person taking a holiday together, and being supported to do so, instead of being restricted to traditional respite care. In particular, we believe that the statutory guidance should link this to Self-Directed Support options (expanded on below).

We do not believe that the requirement on local authorities to give consideration to a short break from caring affords the carer or cared-for person adequate choice or control over their support and believe the provisions within the legislation should be amended.

**Self-Directed Support**

Alzheimer Scotland notes that the content of this Bill runs in parallel to the Self-Directed Support (SDS) legislation and will supersede a number of provisions in relation to support for carers. We believe that within the accompanying statutory guidance, it would be useful to encourage cross referencing to the SDS legislation, in particular to the duties directly relevant to carers. Consideration should be given to this in the context of the Bills provision for information and advice centres within localities and along with considering how the involvement of carers more broadly in the co-production and delivery of services.

Alzheimer Scotland believes that the regulations or guidance should be clear that where a carer has been assessed as meeting the eligibility criteria for support, they should be made aware of the four options under SDS, with explicit reference to the principles of choice and control. Describing the assessment processes in a similar way as in the SDS legislation and guidance would provide consistency of message.
As noted previously, the reference within the Bill to short breaks language could be limiting in nature, creating assumptions being about what a break from caring really means for a person. We believe that it would be useful to include a more explicit reference to the rights of carers, including making them aware of all the relevant information they require to exercise choice and control in their lives. As part of this, more information about the 4 options and mechanisms for increased SDS could help to broaden the thinking in these areas (whilst at the same time reinforcing the values and principles of SDS).

Conclusion

Alzheimer Scotland believes that the Bill in its present form is well intentioned but will benefit from further scrutiny and strengthening as the Bill progresses through the legislative process. Another key factor will be the accompanying secondary legislation in the form of regulations and statutory guidance which will determine its implementation.

Alzheimer Scotland would be willing to support the work of the committee in its scrutiny of the Bill and provide any further information as may be helpful.

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