

‘Caring on the Margins’

The Carers (Scotland) Bill: addressing the challenges of supporting carers in rural, remote and island communities

On the 9th of March 2015 the Scottish Government introduced The Carers (Scotland) Bill to Parliament which sets forward a range of provisions to extend new rights and entitlements to carers and young carers. The Bill includes legislative measures in areas such as carers assessments, information and advice, support and short breaks.

The Challenge of Supporting Carers

Carers are not a homogeneous group. They are all ages, from all sectors of society and they look after people with differing needs. It is therefore a challenging task to introduce legislation which will take into account such a range of requirements. In addition, some caring communities require specific consideration, because they are particularly isolated or difficult to reach. This includes carers from rural, remote and island communities.

This paper looks specifically at the challenges of supporting carers living in rural, remote and island communities and seeks to offer solutions on how the Carers (Scotland) Bill can address these issues, ensuring these carers have equal access to provision and are not disadvantaged by geography.

This paper has been developed by The Coalition of Carers in Scotland’s Rural Working Group, made up of representatives from Shetland, the Western Isles, Argyll and Bute, the Borders, Perthshire and Stirlingshire. It also includes statistical information from the Carers UK report *The State of Caring 2014*, which brings together information from a survey of 5,000 carers across the UK. The statistics in this briefing paper are based on the responses from carers living in rural communities in Scotland who completed the survey.

Challenges for carers in rural and remote communities

The need to take into account the impact of living in a rural and remote area is recognised in the Carers (Scotland) Bill

135. The matters to be specified in regulations which local authorities must have regard to when setting local eligibility criteria would be subject to consultation. **It could be the case that the matters should include consideration of the impact of remoteness and rurality when setting criteria.** The Scottish Government would not want to pre-empt the consultation and it would also be helpful to take the views, prior to consultation, of carers living in remote and rural areas including island communities. **It would be important, however, to consider the impact of geographical isolation on**

the cost of caring and the availability of support services. (Policy Memorandum, Page 29)

The memorandum indicates that there are additional challenges in relation to supporting carers in rural and remote areas and that this impacts on the cost of providing services and their availability.

We are concerned about the ambiguity of the statement that regulations ‘**should include consideration of the impact of remoteness and rurality when setting criteria**’. The intention of these regulations may be to set eligibility criteria at a lower level for carers in rural and remote communities to compensate for the additional challenges carers’ face. However, it could equally be interpreted that eligibility criteria will be set higher to compensate for the additional costs of providing services.

In introducing new rights and entitlements the Carers Bill, must deliver equity for carers from all caring communities across Scotland. If eligibility criteria is set at a higher level for carers living in remote and rural communities this cannot be achieved.

Our position is that rural and remote communities require additional resources and more innovative approaches to ensure carers receive the same **level of support** as carers in more central regions.

Caring on the Margins, the Impact of caring in rural and remote communities

Carers from all communities consistently report that caring has an impact on their finances, their health, their employment prospects and their ability to have a life outside caring. In many instances these impacts are greater for carers living in remote and island communities.

Employment

While unemployment rates are lower in rural areas, carers can struggle to balance caring with employment, particularly as accessing services to support them is often more of a challenge

- 41% of respondents had given up work to care.¹
- 14% had retired early
- 23% had reduced their hours.
- 14% had taken a less qualified job or turned down a promotion

The reasons carers gave for giving up work included:

¹ All statistics are from The State of Caring 2014, Carers UK, responses are from carers living in rural areas in Scotland

- 67% said it was the stress of juggling work and care
- 38% said it was the lack of suitable replacement care services

Financial impact

The cost of living is often higher in rural and remote areas, with increased food, fuel and transport costs. This particularly impacts on carers due to the additional household costs of disability related expenditure

- 12% of carers said they cannot afford utilities like electricity and heating
- 4% cannot afford their rent or mortgage
- 36% are in debt
- 52% are struggling to make ends meet
- 56% say financial worries are affecting their health.

Increased social isolation

Many carers face isolation, but in rural and remote areas this is compounded as there are fewer opportunities for social interaction. Often relatives do not live locally and neighbours are either elderly and housebound, or working and commuting.

Also, in many rural areas public transport is extremely restricted. For example, in Argyll and Bute there are no buses available after 5.30pm and none at the weekend making it difficult for carers to socialise and access services.

- 54% of carers reported that they have lost touch with friends and family
- 62% said that not being able to get out of the house so much had made them lonely and socially isolated

Impact on health and wellbeing

In addition to the physical strain of caring, all the aforementioned factors; juggling caring responsibilities with employment, financial worries and increased social isolation have an accumulative impact on carers' health and wellbeing

- 82% of carers said their health was worse since taking on their caring role
- 3% had had a breakdown
- 15% had to take time off work
- 56% were suffering from depression

An Inequitable System – Support for carers in rural and remote communities

We have shown how caring impacts on a personal level for people living in remote and rural areas. It also has an impact on the provision and availability of support.

Transport

- 67% of carers faced higher transport costs as a result of caring, and this is highest amongst parent carers of disabled children under 18 (76%) and sandwich carers (73%)

Transport costs are significantly higher in rural and remote areas due to the increased fuel costs and greater distances that must be travelled. For example, carers living in Fetlar or Unst who need to travel to services in Lerwick face a minimum 5 hour round trip, which involves 2 ferries and a lengthy car journey. For people without access to a car, travelling by bus, it takes substantially longer.

Where carers require a service in the home, such as replacement care to allow them to have a short break, workers often have to travel for several hours to reach people in remote areas.

In order to recuperate some of these costs, the transport time is typically built into the allocated service, meaning that in real terms the carer receives a much shorter break. In many cases this makes the support ineffective as there is not enough time for the carer to have a meaningful break. For example, to travel to the nearest amenities or visit friends and family.

Access to Services including short breaks

- Only 18% of carers had received a break from caring.
- 37% had experienced increased charges or cuts in services.

Services are less available in rural and remote areas, there is also less choice about the type of support carers can access. This is due to a combination of factors:

- There is more pressure on resources due to the increased costs of delivering services, resulting in a reduction in the level of provision.
- In many rural and remote areas there is very low unemployment. For example, in Shetland the level of unemployment is 3.2%, in Aberdeenshire it is 3.3% and in Orkney it is 3.4%. This is in comparison to Dundee at 11.3%, and North Ayrshire at 13.5%.² This makes it difficult for local authorities to recruit people to work in social care and difficult for individuals to recruit personal assistants through SDS.

² Local Area Labour Market in Scotland, Scottish Government publication, May 2014

Particularly since these are low paid positions and better salaries and conditions are available in other sectors.

This market failure also means that there are recruitment difficulties within the voluntary sector, meaning that assessed service support cannot be fulfilled. For example, we know of a case in Shetland where the carer was allocated twice-weekly 2-hour care attendant visits as replacement care for her mother. However, when the person undertaking this had to retire, no-one was found to replace them.

- Centralised services are not appropriate for many carers and service users due to the time and cost associated with travelling. Therefore building based support, such as day care, may not be an option.

To illustrate the discrepancy between the availability of carer support in rural and remote areas versus urban areas, we looked at the provision of short break services following a carers assessment in Stirling and in rural Stirlingshire.

In both areas carers were assessed by workers from Stirling Carers Centre. Where there was an identified need for a short break they were referred to Stirling council. We compared six cases, three of which were rural and three urban, all had similar levels of need and in all cases the carer was assessed as needing a short break.

All three of the urban cases were allocated support. This took between 3 to 6 months.

None of the rural areas have been allocated support. They have been waiting for between 9 months to 1 year

In addition, when we looked at the figures as a whole from 2014 to 2015, in the urban areas 74 assessments were undertaken. Of these 44% were allocated support and 56% are still pending.

In the rural areas only 29% were allocated support, 71% are still pending. In two cases the cared-for person died before support was put in place and one had an emergency admission to residential care. In one case the carer was waiting for over a year for support for her husband who was terminally ill, but he died before she received any help.

Equal Partners in Care – Hospital admission and discharge

When the person they cared for was in hospital:

- 17% of carers said their expertise was recognised and valued.

- 22% said they were ignored and their caring role was not recognised nor their expertise. 34% said it was sometimes recognised.
- Only 6% were given the information and support they needed

An admission to hospital often results in a person becoming a carer for the first time, or it can signify that their caring role is in transition as the condition of the person they care for deteriorates and there is an increase in their care needs

For people living in rural and remote areas this is a particularly stressful time as they are often many miles from home and away from the support of family and friends. Transport is also an issue and often public transport is not an option. This means that carers who do not drive have to rely on family and friends.

Or in some cases they may not be able to stay with their loved one and the hospital may be a flight or a ferry journey away and this means it is difficult for them to be involved in hospital discharge planning.

Receiving ongoing treatment and support at home is also very challenging, due to travel distances, meaning people are often discharged without adequate support.

Solutions / Best Practice Example

Adult Carer Support Plans

The duty to provide all carers with the opportunity to have an Adult Carer Support Plan is welcome. However, consideration needs to be given as to how this will work for carers in rural and remote areas.

There are several good examples operating across Scotland, where local authorities have devolved their responsibility to carry out carers assessments to local carer organisations. They then provide them with funding to employ outreach workers. Examples of this model are found in the Borders, Stirlingshire and Argyll and Bute. The advantage is that the workers also provide information, advice and access to universal support, such as local peer support groups.

However, it is important that where a carer requires additional services from the local authority there is a quick route into support. The Stirling example we used shows that this system can fall down where local authorities fail to respond in an appropriate and timely manner.

In contrast, in the Borders there are dedicated workers within the local authority who deal with carer referrals. The carers assessment is completed by staff from the carers centre and where the carer requires additional support, such as a short break, they send this to named

staff who deal with it promptly. In practice only a small percentage of carer assessments result in a referral to the local authority.

Non centralisation of support services and the use of community resources

There needs to be greater flexibility and resourcefulness in the delivery of support to carers in rural and remote areas. For example, multiple home visits within one area taking place at the same time, co-location of services within rural community hubs.

The third sector are often more adept at reaching people in remote areas, they do this through the employment of outreach workers, recruiting local volunteers and making the best use of community resources. Examples from our network include:

- In Argyll and Bute the local carers centre in Mind Argyll worked with G.P surgeries to establish local carer support services on the island of Islay. This raised awareness of carers in the area, helped with identification and also meant that carers were offered the opportunity to have a health check. Volunteers were recruited to help to run the service.
- Many of the small inhabited islands in Argyll and Bute are particularly inaccessible, making contact with the mainland very challenging and central posts unworkable. The carers centres in Lochgilphead and Oban have employed outreach workers and local sessional workers to ensure carers in these areas still have access to support.
- On Shetland the local carer centre runs carer groups on the islands of Fetlar, Unst and Yell. They have recruited two local outreach workers who are based in the community, so are already known and trusted. This also cuts down on travel time and expense. They are also exploring the possibility of training carers on Fair Isle on the use of interactive technology, so that they can provide support to carers via Skype. They have already established a virtual carers centre which provides support online and via social media

Self-Directed Support

The Social Care (Self-Directed Support) (Scotland) Act introduced the power for local authorities to support carers and established the principle that charges should be waived for carers. However there has been very poor uptake across Scotland, with only 3 carers in Scotland accessing a Direct Payment since the implementation of the Act.³ By moving from a power to a duty through The Carers Bill, we believe this will open up opportunities for carers in rural and remote areas to find their own solutions to the challenges of accessing

³ Self-Directed Support – The Start, Learning Disability Alliance and NCO, December 2014

suitable support. For example, through the employment family members. This will not be a solution for everyone, but it will provide carers with more flexibility and enable them to draw on more local, community based support.

It is also imperative that the principle of waiving charges for carers is retained with the Carers Bill. We have already outlined how caring financially disadvantages people. As providers of services it would be unacceptable for carers to have to pay for the resources they require to enable them to care.

Employment

Unless recruitment issues are addressed in rural and remote areas, carers will not be able to access the support they are entitled to. While self-directed support may be appropriate for some carers, others will still require a service which relies on the availability of care workers. For example, carers who carry out personal care tasks for the person they care for, must be able to access suitable replacement care for them to be able to take a break. Often it makes sense for this to be delivered within the home. This support is critical for carers in order to sustain their caring role.

We would anticipate that carers providing this level of support would meet eligibility criteria, but unless the support is available they will not be able to access their rights.

We do not have any definitive answers to solving the recruitment problems in rural and remote areas. We think this is an issue that the government and local authorities need to investigate further. However, while the pay and conditions of care workers fails to match other local employment opportunities, local authorities will always struggle to recruit and retain staff.

Staff training – Third sector role

Several of our member organisations deliver carer awareness training to health and social care staff in rural and remote areas. Local carer organisations in Shetland, the Borders and Stirlingshire have all adopted the model of delivering short training sessions within community settings or at staff team meetings. This model works particularly well in rural areas as it does not require staff to invest time in travel, particularly as their post would be unlikely to be back-filled.

Workforce training will be an important element in implementing the Carers Bill and the expertise within the third sector should be utilised. National organisations, such as NES will need to play their role, but in rural and remote areas it would have more impact to resource local third sector organisations to undertake this role.

A Clear Equalities Statement

Carers from BME Communities living in rural and remote areas are particularly isolated as services are unlikely to address any specific language or cultural needs they may have.

Despite commitments in Scotland's Carers Strategy to ensure actions are taken forward to improve equality issues in carer support, there is substantial evidence of differential levels of access to services for carers from minority groups. We believe concerted action is now required to drive forward the limited progress to date and argue strongly that an equalities statement and action plan should be part of the Bill. The fact that most carers are women ensures a gendered dimension is required in assessing the impact of the legislation.

Definition of a short break

We believe a short break should not include travel time and this should be clearly defined within regulations. For example, where the short break includes an element of replacement care this should not begin until alternative care arrangements are in place, freeing the carer to take a break from their caring responsibilities.

Additional Resources

Rural and remote areas will require additional resources in order to implement the Carers Bill and ensure there is equity of provision. Carers must have the same level of entitlement to support as carers in other areas. Rural weighting should be applied to the distribution of resources that go with the Bill and funding must be ringfenced to ensure it is used for its intended purpose

In addition we recommend that additional resources are found for rural areas to specifically address the issue of transport. For example, short break resources should have an additional transport budget to provide rural carers with equity of opportunity and outreach workers will require an adequate transport budget to enable them to cover the most remote and island communities.