

# CARERS Northern Ireland

## Issues paper

### Rural Carers and Poverty

#### 1. Background

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination.

A rural area is usually defined as a community of 10,000 people or less. There are no exact figures for numbers of rural carers. In Northern Ireland, just under 700,000 people live in rural areas.<sup>1</sup> 2001 Census figures show that 11% of the population are carers, which means there are approximately 75,000 rural carers in Northern Ireland.

#### 2. Carers and Poverty

Since *The Cost of Caring* was published by the EOC<sup>2</sup>, there have been a number of studies which have examined the impact of caring on carers financial circumstances. It is clear that caring can have a disastrous effect on carers' finances both during caring and after the caring role has come to an end. Yet, in Northern Ireland alone, their support is worth a staggering £3.12 billion per year to the state<sup>3</sup>.

One of the most recent pieces of research was a survey of 3000 carers across the UK conducted in June 2007 for Carers Week<sup>4</sup>. It found that carers faced severe financial penalties as soon as they start caring for a disabled or chronically ill relative or friend. The survey found carers having to cut back on food, heating and clothes, give up their jobs, sacrifice their pensions - leaving many deeply worried about their financial future.

Carers are often forced out of work because the social care system cannot give them the support they need. They give so much to society, yet due to caring they experience ill health and poverty.

Carers from Northern Ireland took part in the survey, which found that:

- 93% of respondents have found that their financial situation has worsened since becoming a carer, compared to an average of 73% across the UK
  - 48% of carers are having trouble paying gas/electricity or telephone bills
  - 48% are, or have been, in debt
  - 70% of carers have had to cut down on leisure activities because of their financial circumstances
  - 27% have had to cut down on buying food
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- 64% of carers in Northern Ireland have no savings at all
- 77% of respondents worry about their finances either a lot or all the time
- 72% report that this worry is affecting their health
- Looking into the future, 44% of carers expect their financial situation to become worse
- Nearly half (45%) of respondents said they would like to work. But six in ten working age carers said that they could not work due to the level and complexity of the care they provided.

The survey found that caring hits hard in the first year, with carers struggling to cope with the changes in their personal situation and their finances as they start to give up work and have the extra costs of disability. After that, there is a steady decline in their financial situation over time.

Parents of disabled children under the age of 18 and those caring for adult disabled children were worst hit, suffering greater debt and difficulty in paying bills and having to borrow from friends and family.

### **3. Rural Carers – issues identified from research**

Carers in rural areas have the same needs as carers living elsewhere. However, the rural setting in which they live means they face extra barriers of physical and social isolation and lack of services. Additional problems include:-

#### **Lack of services available, lack of choice, lack of specialist services**

Services tend to cost more due to distance needed to travel to and within rural areas. This often means that rural carers are on the bottom of the list for certain services, leading to a lack of choice, flexibility and support. Due to the low numbers involved, there are often shortages of specialist housing, residential and day care. Carers who need specialist services, such as ethnic minority carers or those supporting people with rare conditions and those caring for people with 'stigmatised' illnesses such as mental health or AIDS may have additional problems getting the services they need.

#### **Access to respite and medical services**

Research shows that 52%<sup>5</sup> of full-time carers are never able to take even a week's break from their caring responsibilities. Rural carers also need longer sitting services compared to urban carers, because it takes longer to get anywhere.

Research<sup>6</sup> indicates that older people living in rural areas visited hospitals less frequently, and usually when their illness is more advanced. Only 25% of those living in rural areas live within 5 miles of out-patient appointments, compared with 70% of carers in cities.<sup>7</sup> Rural carers stress the importance placed on GPs making home visits and highlighted the difficulties faced with the closure of community hospitals.<sup>7</sup>

#### **Isolation, companionship and privacy**

Carers UK's survey of its members found that 57% of respondents living in 'remote rural area' suffered from some form of social exclusion.<sup>8</sup> It is very hard to establish mutual

carers' support in remote areas, due to the distance between carers, lack of transport and privacy issues.

Providing services through local means can at times compromise carers' privacy. Carers may fear being stigmatised by the local community, particularly if caring for a person with mental health, or drug/alcohol problems. In some rural areas carers prefer to visit carers' support groups in a neighbouring village or town rather than services in their own community.

### **Alternatives to family care**

Four out of five rural carers considered that they had no 'real choice' about whether to take on their caring roles,<sup>5</sup> there are few alternatives to carers in rural areas and carers tend to be reluctant to look for them due to pressures to portraying images of coping and caring.

### **Information**

Research<sup>9</sup> by Carers UK found almost 69,000 people in Northern Ireland facing new caring responsibilities each year, with 65% of these not recognising themselves as carers in the first year of caring. For a third recognition took over five years.

As a consequence, one in three believed they had missed out on benefits and pension entitlements, the majority (58%) for over three years. Estimates from 2005 indicate that carers in Northern Ireland are missing out on almost £4 million in unclaimed benefits, and are not getting the services or information they need, particularly in the vital first year of caring.

Good, timely, accessible information is therefore vital. However there are very few contact points for information in rural areas meaning that provision of information can be more difficult.

### **Social exclusion: poverty, employment and transport**

The combination of low pay,<sup>10</sup> high transport costs and the high cost of goods and services in rural areas means that many rural carers face the additional problem of living in poverty. Caring on the Breadline,<sup>11</sup> Carers UK's research into the financial situation of carers, identified the difficulties carers face living in rural areas due to the cost of public and private transport. Yet many carers also lack the resources to run a car.

Employment is often seen as one route out of social exclusion. Carers in rural areas, however, can find it difficult to combine paid work, or training and care, due to the lack of transport and difficulties in obtaining support services.

## **4. Rural Carers – Key Issues identified by Carers**

Carers Northern Ireland held a workshop in late 2004 with local Rural Carers to examine what they identified as the key issues.

After much discussion on a range of issues affecting rural carers the key points the group wished to highlight were:

- The key concern was difficulties resulting from isolation, with particular reference to the impact of transport problems in rural areas;
- communication between social worker and carer was felt to be more 'arms-length';
- lack of travel time payments for paid care workers resulted in staff shortages;
- preservation of privacy was felt to be particularly difficult in small communities;
- there were significant problems for carers who lived at the borders between trusts;
- provision of rural housing for carers who wished to live close to the person they cared for without having to actually live with them (there were concerns at the time that changes to planning regulations was going to make this increasingly difficult);
- the need for government departments to be better informed about issues affecting rural carers;
- lack of respite.

It can be seen that the issues self-identified by local carers are consistent with the research findings.

It is also clear that the critical issues regarding poverty for Rural Carers are broadly consistent with poverty issues for all carers. The primary differentials around poverty between rural carers and other carers tend to related to an increased incidence of social exclusion amongst a group that are already highly vulnerable to social exclusion by virtue of their caring responsibilities.

## **5. Problems facing agencies serving rural carers**

- Higher cost of providing services
- Difficulties in consulting rural people
- Rural users and carers may be reluctant to ask for help
- Lack of reliable data about needs of people who live in rural areas
- Staff recruitment/retention problems – “It is still the rural problem. Not being able to recruit staff as helpers for carers in rural villages.”<sup>8</sup>
- Problems in sharing out information
- Poor take-up of services, due to the transport, privacy and other reasons mentioned above

## **6. Legislation and Guidance**

There is no separate legislation for carers in rural areas. However, *Valuing Carers* has relevance. Although there is no specific reference to rural carers, the Strategy recognizes the need for a “range of flexible, practical support ... tailored to fit the needs of users and carers.”<sup>12</sup>

The recent Inspection of Services to Carers of Older People in Northern Ireland<sup>13</sup> indicated that they had found evidence in practice of the difficulties referred to in Section 5 (above). However they stopped short of making any specific recommendations for change in support for rural carers.

It should be noted, however, that the Carers And Direct Payments Act introduced a new duty on Health & Social Care Trusts to inform **all** carers of their right to a Carer's Assessment. Although the purpose of this assessment is primarily to assess health & social care needs:

- A. the Guidance is clear that the assessment must consider whether benefits or other financial or housing issues are a problem, and make appropriate referrals to other public bodies or voluntary agencies that may be able to help.
- B. a carer's need or desire to continue with or return to paid employment should be considered as part of the assessment.

## **7. Suggestions and Solutions from across the UK**

- In Derbyshire an information kiosk was set up at a local cattle market.<sup>14</sup>
- The Connecting Minds Project,<sup>15</sup> run by MIND used teleconferencing to link services users and a trained facilitator to enable carers to communicate with people in a similar situation without any of the difficulties associated with organizing carers groups.
- Babergh District Council set up a Buzz Around service, to pick carers and services users to doctors appointments, shopping, and has also been used to take carers to consultation meetings.
- In Tyrone and Fermanagh, Age Concern's Rural Action on Dementia Project provided day-care in four rural centres tailored to local need, as an effective means of providing respite for carers.<sup>16</sup>
- In Lancashire, day care facilities are used to provide additional services such as visits by GP and district nurse.<sup>16</sup>
- The Northern Fells Rural Project in Cumbria reached isolated carers in seven target areas through articles in a parish magazine and local GPs surgeries.<sup>17</sup> Carers were helped to claim benefits and services, there were local lunch clubs and practical help via a handyman and domestic support scheme.

## **8. Priorities for Action**

- DARD's Anti-Poverty Programme and Strategy should explicitly address rural carer issues.
- DARD's Strategy should include action with other Departments to influence all public bodies to budget for the 'rural premium' – i.e. accept that it will cost more to provide equality of service for those in rural areas.
- Carers need to be involved in consultations about strategy and planning. A copy of our guide to Involving and Consulting Carers is attached.
- Joint working with other government agencies can bring services closer to users and carers by using the nearest available buildings. In particular it may be helpful to work with Health and Social Care Trusts to assist them in delivering on their Duty to Inform carers.
- Two elements are key to combating rural carer poverty:

- good, accessible information that encourages people to identify themselves as carers and promotes timely uptake of benefits for the person and those they care for.

To achieve this the strategy needs to address how DARD, in conjunction with other Departments, can best support community information provision and take-up campaigns. This may include funding rural community groups, providing information online, and signing up to carer-specific initiatives such as Carers Information Network and Carers Rights Day, the benefits and rights awareness day that takes place in December each year.

- Helping to keep carers in work, so they can avoid poverty now, and can keep up long term income and pension provisions, avoiding poverty in later life.

What will assist with this is support for the development of flexible local employment opportunities for carers that will allow carers to juggle work and caring, close to home. In particular, prioritising support for community enterprises and other initiatives in the social care sector will increase the levels and variety of support Trusts are able to provide to carers. This will both increase the feasibility of working for many more carers, and reduce the crippling social exclusion suffered by those who do not wish to or are not able to work.

## References

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