

# 'Carers Rights' Feedback from Discussion Groups May 2009



## **Question One: Participants were asked:**

**What do you think of the idea of working towards a set of Carers Rights? What are the pros and cons of this approach:**

Participants were almost unanimous in their agreement of working towards a set of carers rights. In addition, they made the following points:

- Recognition of carers can benefit some carers sometimes, but not all carers always
- Good practice in respect to carer assessment and flexible use of available resources can also benefit some carers sometimes, but not all carers always
- Rights are absolutely necessary to ensure the 'system' responds positively and consistently to all carers
- Gaining rights could be offset by some form of loss e.g. of public support and sympathy if such rights have to be paid for through higher taxation
- There is the risk of tightening eligibility
- Rights would allow carers to take control of their lives and argue their case
- Rights would give carers more power
- The cost of implementing rights would need to be addressed.
- The growing number of carers would make enforcing a set of rights difficult
- Rights will remove the postcode lottery
- Care 21 recommended a carers charter. A set of rights would be in line with this recommendation
- The challenge of encompassing the different needs of carers in a set of rights

## **Question Two: Participants were asked:**

**What rights should be included in Scotland's Carers Strategy?**

1. Short Breaks: Guaranteed entitlement to breaks from caring (Reference; SNP Manifesto 2007)
  - provision needs to be flexible and needs led
  - respite should be linked to self-directed support
  - Funding should be ringfenced
2. Employment: Right to pursue work and higher education.
  - Carers should have a right to flexible working hours and paid emergency leave

3. Assessments: Guaranteed entitlement to a minimum standard (level) of service linked to outcomes of Carer Assessment or a Direct Payment in lieu of service.

- Carers assessments may be more successful if undertaken by a local carers organisation.
- It should be standard practice to offer a carers assessments prior to the hospital discharge of the cared-for person.

4. Benefits: Guaranteed entitlement to Carers Allowance with no detriment in respect to accessing State pension and other welfare benefit or a guaranteed minimum income for full-time carers (e.g. minimum rate of pay per hour X number of hours of care provided

- Could be capped at 48 hours in line with European Working Time Directive
- Could have annual leave entitlement e.g. 5 weeks, covered by Respite Care

5. Carer Training: Right to training in respect to how to carry out caring role in a way that minimises the risk of harm to self and person(s) cared for.

6. The right to a quality life and good health

7. The right to Information, Support and Advocacy

- Health and Social Services need to develop a systematic process for identifying carers

8. The right to choose not to be a carer

9. The right to recognition as partners and experts in care

- This should include the right to be consulted at all stages of service design and delivery
- There needs to be a clarity of terms. Care Worker to describe paid workers and Unpaid Carer or Caregiver to describe carers)

10. The right for young carers to be children first

**Question Three: Participants were asked:**

**Which of these rights are the most important to you?**

**Group A**

1. Information, support and training
2. Income not benefits
3. Young carers to have the right to be children first

**Group B**

1. Guaranteed minimum income for full-time carers

2. Guaranteed entitlement to a minimum standard (level) of service linked to outcomes of Carer Assessment or a Direct Payment in lieu of service
3. Guaranteed entitlement to breaks from caring

### **Group C**

1. Respite / Short Breaks
2. An assessment resulting in the right to services you are assessed as needing

### **Group D**

1. To have needs met, particularly in relation to Respite / Short Breaks
2. To be identified and consulted
3. To receive appropriate financial support

### **Group E**

1. Quality Short Breaks / Respite
2. Information, Support and Advocacy
3. A pension / wage

### **Question Four: Participants were asked:**

#### **Choose one of the rights from Question 3 and discuss**

- How will this right improve the lives of carers
- How do you see this right working in practice
- What needs to change to make this happen

#### **Group B: Guaranteed Minimum Income for full-time carers**

- There are real and often 'hidden' costs to caring.
- Opportunities to work are limited, as are the opportunities to access education and training to acquire qualifications that would to increase an individual's earning potential.
- A cared for person's income, more often than not, is made up entirely of welfare benefits. The carer, who may also be dependent on welfare benefits, is likely to supplement the cared for person's limited income to ensure they have a decent quality of life, often at the expense of their own quality of life.
- Carers have to constantly plan ahead. This would be much easier to do if there was more predictability about income and state of finances.
- A guaranteed income would make the 'Carer £' very attractive. Market forces would respond to carers' spending power. There would be a wider choice of services. Competition would drive quality up and cost down. Carers' income would benefit the economy by stimulating growth in the human service sector.

## **Group E: The Right to Information, Advocacy and Support**

- This would Improve carers health and wellbeing
- Information is power
- Carers want the dignity of being treated as a human being with rights
- Advocacy would empower carers and ensure they have a voice
- This would improve carers quality of life and the quality of life of the person/people they care for.
- Carers would be less isolated
- Emotional support is hugely important to enable carers to have a life

### **How it would work in practice:**

- Carer Support Workers should be based within health settings
- The network of local carers support organisations should be strengthened and their capacity increased.
- There should be a systematic approach from health and social care professionals regarding the identification, support and signposting of carers
- Carer advocacy should be extended across Scotland.

### **What needs to change to make this happen**

- This should partly be addressed through the Carer Information Strategies
- This should be reflected in Scotland's Carers Strategy
- There needs to be additional resources as well as better use of existing resources
- Health services need to take on more responsibility for provision of these services to carers
- Best practice should be mainstreamed