



**Carers' views on carer awareness training for  
professionals**

**August 2006**

Produced by The Coalition of Carers in Scotland  
10 Kinnoull Avenue  
Dunblane  
FK15 9JG

Tel: 01786 825529  
E:mail: [coalition@carersnet.org](mailto:coalition@carersnet.org)  
Website: [www.carersnet.org](http://www.carersnet.org)



SCOTTISH EXECUTIVE

We are pleased that the Scottish Executive has been able to support the Coalition in this research

## CONTENTS

Page

- 1 Introduction**
- 2 Methodology**
- 3 Purpose and Policy Context**
- 4 Conclusions and recommendations**
- 5 Components of a carer awareness training course**
  - Carers as partners in care**
  - Skills for productive relationships with carers**
  - Understanding of how carers can be helped and how agencies can improve the way they work**
  - Knowledge of carers organisations**
  - Identifying carers**
- 6 Involvement of carers in planning and delivering courses**
- 7 Who carers would like to see taking part in training for professionals**
- 8 The impact of training for professionals on carers' lives**
- 9 Existing carer awareness training**
- 10 Recent changes of attitudes and awareness**
  - Health settings**
  - Individuals**
  - Planning groups**
  - Temporary and fluctuating**
  - Resulting from Carers' Centres and more assertive carers**
- 11 Young carers**
- 12 Summary of recommendations**

## **1. Introduction**

The Coalition of Carers in Scotland formed in 1996 as an information and support network of local carer groups and organisations in Scotland with a focus on collective advocacy of carer needs and a role to monitor and evaluate local impact of national carer policy and service developments.

The Coalition grew in strength with the development of the carers' movement in Scotland and new opportunities to influence devolved government. The Coalition was formally recognised in 1999 by the Scottish Executive and today comprises 66 local member organisations

In October 2005 the Coalition consulted with its members to select its priority areas for monitoring. Carer Awareness Training for Professionals, along with Training for Carers and The impact of Carers Assessments were the key priority areas identified. Funding for the monitoring exercise was provided by the Scottish Executive.

The Coalition's aims in carrying out research on these themes were to show, from evidence from carers.

- where there were gaps between policy and implementation
- where there are examples of best practice
- how carers would like to see services developed in the future.

## **2. Methodology**

The issue of carers awareness training for professionals was explored over the winter of 2005/06 by five focus groups of adult carers and one of young carers. Three of the adult groups and the young carers group had also discussed carers training, the subject of a related report

The five adult groups had different kinds of caring experience:

- Group 1 - 10 people from Argyll and Bute, included carers of children with a disability and adults with physical disability, Alzheimers and mental illness
- Group 2 - 13 older carers (aged 66 to 82), from Glasgow, covering caring experience of physical disability, dementia and mental illness
- Group 3 - 7 parent carers from Inverness and surrounding area, looking after children aged 10-16
- Group 4 - 8 participants in a Coalition of Carers meeting, 3 being carers and 5 representatives of local carer-led organisations
- Group 5 - 10 participants in the Coalition of Carers meeting, 4 being carers and 6 carers organisation representatives.

Almost all carers were "full-time" and between them covered a wide range

of periods of caring, from 18 months to 35 years.

The adult groups were asked:

- what should be included in a carer awareness training course for professionals
- how should carers be involved in planning and delivering courses
- who would they like to see taking part in carers awareness training
- what difference they thought training like this would make to the lives of carers
- if they knew of such training in their local area
- if they had noticed any recent change of attitude or awareness from professionals towards carers.

### **3 Purpose and Policy Context**

In recent years the perception of unpaid carers has changed from passive recipients of services to the recognition that carers are partners in the provision of care. ***The Community Care and Health (Scotland) Act 2002*** was an important milestone for carers in acknowledging them as 'providers of care' for the first time.

This has been further strengthened by subsequent policy including The Kerr Report – '***Building a Health Service Fit for the Future (2005)***', the Executive's response to this '***Delivering for Health*** and the 21<sup>st</sup> Century Social Work Review: '***Changing Lives***'. This sets out a new direction for health and social care provision which places greater emphasis on a more preventative proactive model of care and which recognises the vital role carers play alongside health and social care practitioners in providing care.

The Care 21 report '***The Future of Unpaid Care in Scotland (2005)***' and the ***NHS Carer Information Strategies: minimum requirements on guidance and implementation (2006)*** mirror many of the same messages around, early intervention, the personalisation of services and the need for increased recognition of the role of unpaid carers. In addition Care 21 projects a bold vision for carers in Scotland – based on a strong framework of rights – where the contribution of carers to society is fully recognised and where carers are valued and supported.

Much of this evolving policy will require, not just a change in service design and practice, but a change in the culture of organisations. It requires staff from health and social care sectors to embrace new concepts and to adopt new working practices. In particular, it requires them to take more account of the views of carers and fully involve them in service planning and decision making at all levels. Carers awareness training is an essential component in delivering these

changes and has been highlighted as an immediate priority.

This report brings together the views of carers in order to consider the content, design and delivery of training programmes. It also aims to highlight the value which carers place on staff training and the positive difference they feel it could make to their quality of life.

#### **4 Conclusions and recommendations for future developments**

This report demonstrates the wide-spread and strong feeling amongst carers that the effectiveness of their role would be increased if professional workers were educated in understanding and responding to it. These views are held by adult and young carers alike.

The role of carers in assisting the move towards the self care model of supporting people with long term conditions cannot be underestimated. If health and social care professionals are trained to recognise carers as true partners in care this will benefit not only the carer, but also the people they care for and the NHS. Thereby resulting in better outcomes for the person they look after, fewer hospital admissions and a decreased risk of the caring role breaking down.

This study strongly supports recent policy which places emphasis on carers awareness training and recommends the following steps should be taken to assist in the implementation of this policy:

**Recommendation 1: Key staff need to be identified locally to take lead officer responsibility in the design and delivery of carer awareness training programmes.**

The ***NHS Carer Information Strategies: minimum requirements on guidance and implementation (2006)*** requires an accountable manager within each NHS Board to be identified to oversee local strategies, which must include a detailed action plan for the training of staff. Other key sectors such as social work and education would also benefit from adopting this approach to ensure there is widespread deliver of training

In some areas in Scotland, such as Glasgow, a joint working approach has been very successful in developing and delivering carer awareness training to staff from social work, health and education. As well as making the best use of resources this has also ensured there is a consistent message being delivered to staff from different sectors.

**Recommendation 2: Carers Awareness Training should be delivered as widely as possible to staff at all levels and should be built into training**

## **and education programmes, induction programmes and continuous professional development.**

Many carers believe that understanding of carers, their role and its effect on their lives, should be built into training and education programmes for everyone likely to come in contact through their work with carers, not just health and social care staff, and that greater awareness amongst the general public is also needed.

Developing such informed professional awareness is widely seen by carers as an essential element in achieving the vision of the **Care 21 Report** and other key policy areas.

### **Recommendation 3: Carers must be involved in the design and delivery of training and in monitoring outcomes. Resources need to be made available to assist carers in participating**

The groups of adult carers who contributed to this report unanimously agreed that *"carers should be trained to be 'expert carers' so they can participate in training professionals."* They felt that carers would require training and support, including access to adequate short break provision to enable them to participate effectively. They also suggested that carers should receive payment for their contribution.

This model has already been developed successfully in many areas of Scotland with carers contributing to training courses and introducing a personal element into the learning process. Participants tend to rate this part of the course very highly.

### **Recommendation 4: Carers Awareness Training must reflect the needs of carers from all caring communities, including young carers and carers from an ethnic minority**

The caring community is a large and diverse one and encompasses people of different ages, different social backgrounds and from different communities. There are many additional factors which require consideration if professionals are to become fully 'carer aware' and these need to be reflected in the design and delivery of training programmes. This includes the specific needs of young carers, the language, cultural and support needs of carers from an ethnic minority and the needs of carers living in remote and rural communities.

In the case of young carers, professional ignorance can damage their educational and personal development. In this study, the young people's emphasis on the effects of caring on their own lives confirmed the importance of supporting them

as children first, as set out in the Care 21 Report: '***The Future of Unpaid Care in Scotland***'

**Recommendation 5: The outcomes for carers should be closely monitored to ensure that training courses are successful in delivering change and ensuring policy is translated into practice.**

The Scottish Executive has embarked on an ambitious programme of health and social care reform which will require organisations to change the way they view the users of their services and their carers. Training for staff is essential to ensure that these changes are understood and embraced. To ensure training is effective in delivering these goals we recommend that the outcomes for carers are closely monitored by involving carers directly in the monitoring and evaluation of training programmes.

## **5 Components of a carer awareness training course**

The five adult groups suggested – in different ways reflecting their composition – five main components for carer awareness training courses:

1. Develop attitudes to regarding carers as partners in care: Carers felt strongly that professionals needed to develop their understanding of the contribution carers make to health and social care provision. Carers wanted professionals to listen to them more and value their experience and knowledge.
2. Develop skills to facilitate productive relationships with carers
3. Develop understanding of carers' needs of help and how agencies can improve the ways they work, to be more helpful to carers
4. Develop knowledge of carers organisations
5. Develop awareness of the value and knowledge of the means of identifying carers.

### **Carers as partners in care**

Approaches to the primary component (i.e. 1 above) were somewhat different between the 3 area-based groups of carers and the 2 Coalition groups. The latter demonstrated their knowledge of the case for carers built up by their own and carer colleagues' work over many years and recommended a comprehensive range of topics from research, national policy documents and laws:

- definitions and statistics

- definitions 'what is a carer', what they do
- definition of respite – regular and substantial
- laws and regulations in relation to carers
- carers assessment – how to complete and rights to carers assessments
- equality perspective
- empathy – looking at a carer's whole life
- recognising diversity of caring situations. . the particular needs of different caring roles
- valuing and recognising carers as 'partners in care'
- contribution of carers to society and the economy
- impact of caring on carer's own life and healthy
- back-up evidence
- implications if carers aren't supported.

The 3 other carers groups also wanted increased knowledge and valuing of carers and suggested as training topics and approaches:

- carers' health
- carer rights, e.g. to an assessment. Nobody in this group had ever been informed of this right by a health professional or social worker
- listening to carers – they know the person they look after best
- to listen, understand and value what carers have to say
- walk in carers shoes – shadowing carer – before putting together a care package, look at the family's 24 hour needs.

### **Skills for productive relationships with carers**

All groups, particularly the 3 area based groups, had suggestions for improved interpersonal skills:

- listening skills, counselling skills
- dignity and respect for the patient and carer – listen without judging
- training on listening to carers and treating them as 'partners in care'
- empathy and team building
- communicate with carer and listen to them
- communication/listening/respect
- use of language
- bedside manner.

### **Understanding of how carers can be helped and how agencies can improve the way they work**

All groups suggested training in what would help carers, both in how their needs were met and in how services were organised:

- what carers need
- include carers from the beginning – don't meet with carers after the professionals have met together
- making sure carers get help at an early stage – helping carers cope with

- diagnosis
- providing appropriate information on the illness/condition, or referring carer on to appropriate person for further information
- assisting carers to deal with aggressive behaviour
- prioritising carers e.g. when making appointments at health centres
- follow up and review ( need to follow up assessments with action; take account of the changing role of carers)
- communication between agencies and workers from the same agency. For example, the lack of information exchange between consultants and G.P's
- referring to specialists and passing on to other agencies for advice and information
- working with other staff - coordination
- feedback system – communicating from the bottom to the top
- taking action quickly, informing carer of treatment
- think carer integrated into all services
- use of person centred plans – as suggested in Care 21
- making services accessible to carers
- giving benefits advice – one carer had been given wrong advice by a Helpline which led to them failing to claim a benefit to which they were entitled.

### **Knowledge of carers organisations**

The two Coalition groups had most to say on this. Suggestions for training input were:

- information on local carer organisations
- highlighting partner organisations
- resource pack – local carer services

### **Identifying carers**

Both Coalition groups recommended including training in the use of carer identification tools.

## **6 Involvement of carers in planning and delivering courses**

All adult carers thought carers should be involved in planning and delivering courses, “from the very beginning”, “all the way through”, one group adding specifically “at the evaluation stage to see what worked”.

There was some unanimity that “carers should be trained to be 'expert carers' so they can participate in training professionals.” Carers would also need support in preparation and in delivery, adequate back-up care provision and payment for their contribution.

One group added that it was important that carers did not contribute as isolated token carers. It was suggested by one group that former carers should be targeted to undertake this training work.

It was acknowledged that all of this would require resources.

## **7 Who carers would like to see taking part in professionals training**

All groups except group 2 specified a very wide range of people they thought should have training about carers, summed up by one group as "everyone who comes into contact with carers". Another group suggested a national publicity campaign.

Statutory and voluntary sector services included education, housing, culture and leisure, the police, youth services, Citizens Advice Bureau, legal profession, Benefits Agency, as well as all health and social work services.

Most groups said that carer awareness training should be built into education and training through links with universities and core training programmes. All levels of service personnel should be involved as well as those such as GP s, nurses, social workers responsible for direct health and social care service contacts:

- student nurses and social workers
- front-line staff such as receptionists, janitors and drivers,
- care workers and personal assistants
- teachers
- service planners, managers and chief executives, councillors.

## **8 The impact of training for professionals on carers' lives**

The groups were asked what difference they thought this kind of training would make to the lives of carers. All groups believed it would make a huge difference, two groups seeing it as remedying deficits of understanding and prioritisation and leading to similar improvements in health, well-being and service support as they had envisaged for carers training. Group 1 said simply "We aren't asking for much – simple things can make a huge difference . . . it would make a huge difference to be listened to".

The two Coalition groups saw this kind of training having the potential to achieve the recommendations of the Kerr Report and Care 21. It would lead to carers' needs being acknowledged and met early in their caring experience. This, plus more sensitive and informed treatment as 'partners in care' and provision of more effective services through carers assessments, would result in caring roles being more fulfilling and sustainable and carers

being healthier and happier, their lives having better balance and choice, including employment.

## **9 Existing carer awareness training**

Groups were asked about the existence of this kind of training in their areas. The Argyll and Bute and Highland groups were not aware of anything happening in their areas. Specific programmes were reported by the other three groups in eight different areas, plus a Carers Scotland carer awareness training programme "delivered widely".

The area programmes reported were:

- Aberdeen: dedicated post to raise carer awareness with GP s and other healthcare staff
- Grampian: carers have taken part in training courses for student nurses
- Edinburgh: half-day training course supported by a training pack, carers involved in pack production and training delivery. Difficulties with finding volunteers to deliver training were reported
- Glasgow: similar course developed, plus a video which is used in some areas. Although the video shows carer experience it is reported to be not so effective as direct carer participation. Case studies and quotations also had impact. Carers Centre carers have contributed to design and delivery of these courses. NHS Greater Glasgow employs a dedicated carer co-ordinator whose remit includes this type of training.
- Borders: trainee nurses come to the carers support groups
- East Dunbartonshire: Carers Centre delivers workshop on carer awareness to social care workers within their protected learning programme
- Lanarkshire: Carers Centre provides core training for social work staff, contribute to induction for home care staff, deliver young carer awareness training. All training includes carers, "which has a major impact".
- Stirling: Carers Centre has a monthly training session with nurses.

## **10 Recent changes of attitudes and awareness**

Groups were asked whether they had noticed any recent changes in attitude or awareness from professionals toward carers. All groups reported some localised changes but also 'no' or 'not much' change overall, although one of the Coalition groups agreed that "Things are more positive than they used to be".

Improvements were noted as:

- in some health settings
- from individual workers
- within planning groups
- temporary and fluctuating
- connected with Carers Centres and through carers themselves being more assertive.

### **Health settings**

Improvements in health settings were reported by 4 groups:

- consultants treat carers as 'partners in care' but not the lower levels (Group 1)
- some change in hospitals with an improved attitude (Group 2)
- there are some improvements within acute trusts, e.g. better information and consultation at hospital discharge – packs have been developed in some areas with good positive outcomes e.g. preventing bed blocking and better ongoing services (Coalition group)
- new people coming into post are often more open to listening to carers; 2 carers experienced this with a new GP (Group 3).

### **Individuals**

Individual examples of good practice were notable as the exception to general lack of change:

- one carer who reported an “excellent social worker who always listens and even brought flowers after a bereavement” prompted a response from others in the group that their experience was different and it was down to individuals, not universal experience of improvement (Group 2)
- group consensus – some individuals have a good attitude to carers but there has been no perceived change in overall attitudes (Group 3)
- it's very patchy - some have listened and helped – others have got overloaded and left (Group 1).

One group saw the lack of staff movement in their rural area preventing new people bringing in changes in attitude. This was seen as happening in areas with high staff turnover but not where staff often stay in the same job for many years and are unlikely to change their attitudes. (Group 3)

Staff workload was seen as an impediment to greater responsiveness to carers:

- not much change – social workers are always busy (Group 2)
- staff always seem to have a lack of time, they don't recognise carers' skills or value (Group 1)

### **Planning groups**

People who had been involved in planning groups thought they had been

more genuinely involved than previously and that attitudes had improved at higher levels, but not at lower levels (Group 1).

### **Temporary and fluctuating**

Improvements fluctuated:

- after training referral rates go up for a period then down again
- yes and no – some don't change even after receiving training and still view things as resource led

### **The Success of carers organisations and carers in effecting change**

Two groups (Group 2 and a Coalition group) thought the work of carers organisations had improved professional awareness as well as making life better for carers:

- there are more referrals to Carers Centres
- the Carers Centre has made a big difference – the Carers Group is excellent
- there is more information out there – but carers still need to look for it, it is not handed to you, except at the Carers Centre.

Carers own increased assertiveness was all important:

- carers know their rights and are more likely to stand up and demand their rights
- carers still need to know the system and battle for services.

Carers “who don't fit into the right boxes” still had difficulties and ethnic minority carers were still disadvantaged by myths and stereotypes, such as “they prefer to look after their own”.

## **11 Young carers**

Young carers were asked if they thought people like doctors, social workers and teachers needed to learn more about young carers, and what sort of things they needed to learn.

There was agreement that all professionals did not know enough about young carers. Specific criticisms were:

- Teachers, who
  - “just boss you around”
  - “ignore you and are always busy”
  - “don't listen to your problems”
  - “didn't tell me about the Young Carers Project” (referring to a guidance teacher)
- Social workers, who
  - “don't come often enough”

- “don't talk to me”
- “only talk to me, they don't talk to my sister (who has a learning disability).”

No-one in the group had had any experience of doctors.

The group thought that all professionals should know

- what a young carer is
- about the Project so they can tell people about it.

They thought that professionals should be able to

- listen to young carers and make sure they know what's going on
- be more supportive, for example when they were tired in class or homework is late, or they are worried about problems at home.

They thought the best way for people to learn about young carers was for professionals to speak to young carers, and for head teachers to speak to pupils and also for pupils to learn about young carers in lessons.

They thought priority groups for learning about young carers were teachers (especially guidance teachers), other pupils and social workers.

Improvements they thought would come from this learning would be:

- at school:
  - teachers would talk to them about their problems and give them help. They would no longer get into trouble if they were late or were unable to do their homework. Guidance teachers would be able to help them and direct them to other help such as the Young Carers Project
  - other children at school would stop teasing them and they would feel free to talk about being a carer instead of feeling embarrassed and hiding it.
- at home:
  - social workers would come more often and speak to them as well as other family members. They would listen to them and be able to point them to sources of help.

## **12 Summary of recommendations**

Recommendation 1: Key staff need to be identified locally to take lead officer responsibility in the design and delivery of carer awareness training programmes.

Recommendation 2: Carers Awareness Training should be delivered as widely as possible to staff at all levels and should be built into training and education

programmes, induction programmes and continuous professional development.

Recommendation 3: Carers must be involved in the design and delivery of training and in monitoring outcomes. Resources need to be made available to assist carers in participating

Recommendation 4: Carers Awareness Training must reflect the needs of carers from all caring communities, including young carers and carers from an ethnic minority

Recommendation 5: The outcomes for carers should be closely monitored to ensure that training courses are successful in delivering change and ensuring policy is translated into practice.