Discussion between Carers and MSPs from Health and Sport Committee
Notes from session facilitated by Carers Scotland

Group 1

General

- Two major problems for carers:
  - Caring for their loved one
  - A system that should be there to offer support but often doesn’t
    the latter creates greater stress
  - Often do not need to create new legislation, simply need authorities to adhere to the laws and guidance that is already there.

Inspections

- Need more unannounced inspections…indeed should all inspections be unannounced?
- When carers are surveyed during inspections this should be done directly by SCSWIS rather than though the local authority. Felt that there was a chance of “cherry picking” where carers that had poor experiences were not included.

Staff and inspections of services

- Significant concerns over the hours and rota that care staff are working
  - Suggest that inspections including examining a sample of rotas from care agencies to investigate whether it is feasible to provide the care they are allotted to provide within the hours available without providing a very reduced service to the service user.
  - Staff are working too many hours, often exhausted and because of this service can be poor. One carer suggested a tachograph similar to that used by lorry drivers to ensure that staff are working appropriate hours with sufficient breaks. Concerns over safety.
  - There appears to simply not be enough time for staff to complete their duties.
- Also concerns about the level of training of staff:
  - Training and development should form part of inspection process including verification of what training has been undertaken rather than simply what is offered or claimed to be available.
• Care workers are often inadequately trained, particularly in health
related care including dressings and catheters. This often leaves
the carer having to carry out these tasks.
• More training is needed of staff on working with people with
communication difficulties.

Service provision

• Concerns over recruitment and support of care workers and valuing the
service they provide.

• Lack of flexibility.

• Carers worry about the lack of continuity of care – often different care
workers.

• Assessment is not needs driven or person centred but rather financially
driven. Assessment is inconsistent and variable and there is difficulty
in both getting an assessment or review when things change and how
quickly this can be done.

• Essential life planning is one approach that can ensure continuity of
care and provide flexible services to individuals.

• Carers asked “who is the customer” – is the cared for person, the care
or as it appears to be, the social work department.

• Lack of equity between the care provided to those with some terminal
illnesses v the care available to people with dementia.

• Carers noted the importance of the role of the GP. Critical in facilitating
support and in supporting and advocate for the carer.

• Real concerns that procurement is driving down the quality of care.

• Hospital discharge is a real sticking point. It is often simply not good
enough. Feel that this is a key area that inspections should focus upon –
in particular on whether assessments are carried out before leaving
hospital and whether services are provided on discharge.

• Issues around costs…it appears that local authorities are more willing
to spend c. £750 per week for residential care rather than providing the
required level of care at home which would cost less and enable the
person to stay in within their own homes and communities supported
by their carer.
Complaints

- Carers want to be able to complain about services without consequences. They want to protect relationship with care workers.
- Concerns over the length of time taken to deal with challenges and complaints.
- Would like support and advocacy to raise issues outwith the complaints procedure (and know that they will be listened to and the complaint acted upon).
- There is an urgent need for more independent advocacy for carers.

Group 2

Some key points raised:

- There is scope for Health Committee in this review of the regulatory regime to look at how the wider social care system operates and how it is also regulated. Particular concerns were raised about barriers at local authority level in terms of accessing support for both carer and cared for, money deemed to be ‘wasted’ by local authorities in terms of work delivered (e.g. adaptations) and in carers and cared for frequently having to fight for the support they and their families needed, and in taking their cases further e.g. to senior managers, elected representatives (MSPs/Councillors)
- Red tape/bureaucracy and culture/communication issues represent an added and stressful burden for unpaid carers and their families. Examples of bad professional practice from educational psychologists, social work officials/managers were provided; waiting lists and perhaps unnecessary bureaucracy around self-directed support/Direct Payments can put substantial pressure onto carers who want to take up these options. In one case, carer of adult son with MS and Dementia spoke of waiting 18 months to access a Direct Payment, alteration work having to be redone because the cared for person’s needs had changed – and this would not have had to happen if carer had been listened to in planning for the alterations needed. The carer also expressed real concern about the time/money involved in the process to access Direct Payments.
- Strong feelings expressed by group that complaining leads to less good service or ‘threats’ from professionals that services already provided will be lost.
• Treating unpaid carers as equal partners in care could prevent some of the issues and barriers picked up by inspection regimes – listening to unpaid/family carers who often know the cared for person well. Better communication and a focus on families would help immensely.

• Awareness of unpaid carers often poor and involvement in decisions around family members limited. E.g. decision to place autistic child in a special school did not involve parents and communication of decision made via a phone call to mum who had English as a Second Language.

• How are professionals who operate within the social care system regulated? e.g. Educational Psychologists. In this case, the decisions that they are involved in can have quite profound impacts on the lives of the child and of the parents too. One carer felt that she had been bullied by an Educational Psychologist.

• Quality also of home care services was raised (Glasgow) and lack of ‘client centredness’. Lack of continuity/quality of care, unpredictable arrival times, and different home care workers coming presented real challenges for one carer who supported his 90 year old mum who had visual impairment and Alzheimers’. He felt strongly that the needs of his mum and his needs as a full time carer were not being listened to.

• Lack of connectivity between health service and education (e.g. for disabled children) a key issue. Who regulates this?