

Date: Wednesday 26 May 2004

Venue: Committee Room, National Assembly for Wales

Title: Report on Focus Groups

1. Attached are reports on two of the three focus groups run by the Committee's Expert Adviser, Professor Vivienne Walters, in conjunction with Age Concern Swansea. The draft report of the third group has been sent to participants for clearance and will be circulated as soon as it is available.

Committee Service

May 2004

Annex 1

Review of the Interface between Health and Social Care - Report of a Focus Group with staff from Age Concern

March 2004

The focus group involved six staff members and one volunteer with Age Concern. The following points emerged in the discussion.

Hospital discharge:

- if a person has a carer, nothing has improved in the past 10 years. An example from the previous weekend was cited:

a man was discharged too early, help was not in place, there was no referral to social services, no care assistant was provided, the carer was not told she would have to change a catheter and she had none of the equipment she needed (such as a commode and a backrest). Because it was a weekend nothing could be done.

- discharge planning does not start as soon as a patient is admitted to hospital. One participant in the focus group (who 'knows the system') told of the problems she had encountered. She felt powerless in acting as her father's advocate.

when her disabled father in his early 80s (deaf, asthmatic and with only one leg) was admitted to hospital, they waited from 5.00 'til 11.30pm and when they got a bed, there was no porter. She described the confusion over his treatment as being 'Third World medicine'. He was discharged without his care being completed and with no care plan or contact with social services, even though she had requested this; no one asked her whether she could manage. He was readmitted 3 days later when he collapsed, but there is still no mention of discharge plans.

- nurses see things differently, 'they don't see beyond the bed' and neglect the emotional and social side of patient needs. Ward staff do not know where to refer patients. No one knows what other people are doing and how they can work together
- patients and carers face major problems in obtaining information in hospital and in finding out what is likely to be happening, when they might be discharged and what care will be put in place.
- it is often assumed that carers are relatively healthy and that they can cope, yet often this is not so. Carers may have health problems of their own and it may be a considerable struggle to fulfill their caring roles. Even those who do enjoy good health can develop physical and mental health problems as a result of their caring responsibilities.

The revolving door:

- patients too often are discharged early with no effective care plan in place and they find

themselves back in hospital within a few days. In these cases they are typically processed in A&E yet again, repeating the same procedures, rather than being readmitted to a ward.

- some patients are kept in the holding bay overnight and then discharged without a discharge plan/care assessment. This increases the likelihood of them returning to hospital.
- the day hospital in Morrision has been closed and the vast majority of patients (often from the Valleys) have been readmitted to hospital. It had been a valuable resource which patients attended 1 day a week for checks, and which helped to reassure carers.
- many of the problems faced by older people are not self limiting and yet service provision appears to assume that this is so. Care plans are set up for a period of six weeks. After that, it is not clear who bears responsibility for continuing assessments of need and changes in plans to reflect a gradual (or more immediate) deterioration in health or level of ability. Care assistants are generally low paid and relatively unskilled, yet appear to be responsible for monitoring patients.

The needs of some types of people are neglected and this can lead to a deterioration in their health and greater demand on services than might otherwise have been the case:

- people who fall below eligibility criteria yet who do need low level assistance with tasks of daily living such as shopping, house cleaning, gardening, washing nets and so on. People's embarrassment about the cleanliness of their house can prompt social isolation and this in turn can prompt other problems. Help with filling out forms and claiming benefits is also crucial. In one instance a man simply needed cookery lessons. If there is a carer and s/he is also frail, there is a risk that both will 'slip through the net'.
- attention is often focussed on those who are 75 years and older. This means that people who are 50+ receive less attention, yet this is the age group where preventive work/health promotion is most valuable.
- people who refuse services may have considerable need for help. This is where voluntary organisations such as Age Concern appear to play an important role in building trust and helping people. Two of the examples cited in the group are:

(i) a woman who refused care - Age Concern persisted and regularly visited, talking with her through the letter box. When she did let them into the house, they found she had a wet bed, no heating, no way of heating food and walls that were running with damp. They helped with food and warmth and made her aware of other services, including housing. She is one of their clients.

(ii) a fellow with a false arm who was knocked down by a car had little knowledge of services available - Age Concern were able to gain his trust and found that he was

heating his room with a toaster weighted down with a brick and leaving huge burn marks on the carpet. Because of a stroke he could not put money in his gas meter and he was not able to do his garden. They helped him apply for benefits which rose from £57 to £172 with a back payment of £1,000. They got him a microwave, arranged for him to see a dentist and got him fitted for a new arm as the other had been damaged in the accident. 'He got control of his life again'.

Differences between Age Concern and Statutory organisations

- staff at Age Concern felt that they could work in a different way than those employed by statutory organisations. They are able to build up trust and be persuasive, they can adopt an holistic approach, they are able to give their time more freely, they can be person centred and they can bridge gaps.
- in contrast, they portrayed people working in statutory organisations as being task centred, following narrow job definitions, ruled by structures of responsibility and not seeing people as human beings but as 'care packages' or 'hours'.

General Practitioners:

- GPs were criticised for not being very helpful, especially in the 5 - 6 days after discharge when they will not visit a patient.
- it was felt that they would often typecast patients and may refuse to attend. Because the patient had 'cried wolf' so many times, one GP refused to attend a woman who fell in the night and thought that she had broken her hip. The woman called Age Concern who, in turn, called an ambulance. She had broken a bone.

Joint working:

- joint working will take place but will be 'painful' - boundaries of responsibility will have to be blurred and people will have to see beyond their narrow remit.
- it will be necessary to look at underlying problems (adopting a broad rather than a narrow approach)
- it will be difficult because of the different cultures, levels of responsibility and decision making in different sectors. One person felt that senior managers were like children in tackling these issues and she said 'I'd like to knock their heads together....'

Best practice:

- Age Concern is responsible for a hospital discharge scheme. It includes nurses and social workers who work together outside their normal structural limitations. Working jointly requires a blurring of boundaries and feeling responsible for things beyond their usual remit. [I have included documentation on this.]

Changes they would like to see implemented:

- readmissions of older people should not take place through A&E
- discharge planning should start when the patient is admitted
- there should be one discharge co-ordinator on each ward to ensure that the work proceeds smoothly and that plans are in place before a patient is discharged.
- there should be one point of information for carers and patients who currently face major problems in accessing information about care and future possibilities, including problems such as how to get a bed downstairs.
- greater sharing of information between services should take place and there should be a single case file open to all practitioners
- practitioners often do not appreciate what each other do in the course of their work. There needs to be some way of finding out what everyone does. This would help with patient assessments and the development of appropriate care plans.
- joint health and social care day centres would promote joint working and would allow 'one stop' care for patients who need several tests/procedures. It would save them travelling 'all over the place' for different tests on different days.
- more funding for Care and Repair who are overstretched and unable to respond as quickly as they have previously.
- care assistants should be better paid and better trained. They carry a considerable responsibility in monitoring a client's progress/deterioration.

Annex 2

Review of the Interface between Health and Social Care - Report of a Focus Group with Users of Services

March 2004

The group was made up of 3 women who are carers and 6 people who receive or have recently received care. They ranged in age from 56 to 93 and, as their participation in the group indicates, they are not completely housebound. The following are the main themes which emerged during the discussion.

Feeling a sense of control

- several people spoke of the importance of having choices and feeling that they retained some control over their lives. This was particularly pronounced for one woman, a carer, who had been told that she and her husband would have to sell their house because (seemingly simple) modifications - the construction of a ramp - could not be financed by the local authority. After a series of other housing problems she said that 'I feel everything has been taken out of my hands'.
- social workers can be very important in providing clients with information, which can increase their sense of control. The importance of having information was a *very* strong theme: information on services, entitlements and who to contact when in need of help.

Staying in your own home

With only one exception, people wanted to stay in their own homes and felt that they should not be compelled to sell homes that they had struggled to pay for.

- it was a source of great stress for one woman when she and her husband had to sell the home they had lived in for about 40 years. She said 'I miss my garden terrible'. She felt she had a relationship with her garden which had a tree for each of her grandchildren.
- one woman said that she had struggled to pay for her home after her husband's death and she refused to sell when told to do so by social services.
- no one wanted to go into a 'home'; the feeling was unanimous, even though they recognised that there were good as well as bad residential homes. People wanted to die in their own homes and they felt that the changes in health and social care over the past 5 years or so made this more likely.
- one person had sold her house and moved to sheltered accommodation. For her, it was the best solution but others were more emotionally attached to their homes and perceived sheltered accommodation as too cramped and likely to change their way of life. They said that they did not want to live surrounded by nothing but old people.

Social Services

- the care provided by social services was praised in many ways. People spoke highly of their

social workers, their carers, respite care, rehab and day centres; Earlsmoor was praised by several people, as was Care and Repair. There was no mention of poor co-ordination of services; 'it all fell into place'. One woman said she was so poorly, she didn't know what was happening, and she was well cared for. Another said 'I didn't know who or where I was' and was full of praise for the help she received - 'it was wonderful'.

- yet public resources are too few. The participants in the group spoke of waiting lists for respite care and wondered how many people were waiting for this. Carers were not available in a crisis and when one woman broke her arm she had to turn to private care for the extra help her husband needed. Several people were limited in the number of days they could go to day centres and they said that there were waiting lists for these, too. Provision of stair lifts and hoists was inadequate and one woman had to pay for her own, even after being told that a grant would cover a replacement stair lift (she was now in debt to her daughter). Modifications to their homes were also a problem (e.g. waiting times for Care and Repair) and these were not necessarily funded by the local authority, though they were crucial in maintaining people's independence.
- in several instances people had to pay for equipment or modifications themselves. They bought hoists, installed stair lifts, hired their own carers. In some cases, they did not know what help was available for them. In other cases, the waiting lists were in excess of a year or two and they felt they could not wait so long.
- private carers are not as good as care assistants funded by social services; this point was made forcefully. One woman spoke of their obvious lack of training and felt it was inappropriate that she had to train them.

Information

- this was a key issue than ran through the discussion. People spoke of the confusing range of agencies and providers involved in their care and often had no idea who was providing the services they received.
- typically, people did not know where to go for information or who to contact if there was a problem.
- they did not know the extent of the services that were available to them and the focus group was probably helpful as a means of sharing information.
- one woman said 'you only find things out when something happens' and while this might be appropriate, it was clear that people often did not know of their entitlements or the choices they might have.
- a discussion of how information could be made available touched on enclosures with pension

books or council tax forms, leaflets in doctors' surgeries, and a card such as the NHS Direct cards that could be kept on the 'fridge. The consensus was that one telephone number should link them with a real person (no recorded messages) who could provide information and point them in the right direction.

Family

- several women relied on their families for help. For example, one could not go out alone and she relied on her daughter or her grandson. Another relied on her daughter who lived next door, but the daughter was almost 70 and not in good health.
- the dedication of family carers was obvious and one woman described it as a 'labour of love'. They made many sacrifices and in some cases their own health suffered. One woman described how her back problems disappeared when she and her husband bought a hoist to lift him. Another woman had several health problems and was experiencing considerable stress as a result of housing difficulties.
- the importance of having a carer's assessment was emphasised by one woman who had gone through this process and found it very helpful. Never before had she been asked what would make her life easier. As a result of this she was taking driving lessons and she also had a mobile phone, both of which promised to be a tremendous help.

Policy initiatives

These are the strongest themes that emerged when people spoke of the need for change:

- better pensions - the recent increase in pensions was completely inadequate in the light of other cost increases (such as the council tax).
- better access to information
- more invested in local authority services so that respite care, carers, day centres, modifications to their homes, and equipment such as hoists are more accessible.
- better training and supervision of private carers.
- better transport and more buses with low platforms and sympathetic drivers.
- incontinence pads should be delivered to people's homes.

People wanted to be able to stay in their own homes but with appropriate help for their varied needs.

They spoke highly of Age Concern, services in Bonymaen, Care and Repair, the Carers' Association, Earlsmoor and Gwenda Thomas.

NOTE: The discussion could not capture the experiences of patients who are in hospital or on the brink of being discharged, clients who are housebound bound (except through the views of their carers) and people who have refused services.