

## 6. PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES

**FOCUS GROUP:** PEOPLE WITH PHYSICAL AND SENSORY  
DISABILITIES

**VENUE:** BALMORAL TRAINING RESOURCE  
CENTRE, BELFAST

**DATE** 14<sup>TH</sup> APRIL 2004

**NUMBER OF  
PARTICIPANTS:** 6

Profile of Participants			
		Number	%
Sex	Male	3	50
	Female	3	50
Age	Under 18	-	-
	18-24	1	17
	25-44	3	50
	45-64	1	17
	65-74	-	-
	75+	-	-
	No Answer	1	17
Disability	Yes	5	83
	No	-	-
	No Answer	1	17
Dependent Children	Yes	2	33
	No	4	67
	No Answer	-	-
Other Caring Responsibilities	Yes	-	-
	No	5	83
	No Answer	1	17

## 6.1 PRIMARY CARE SERVICES

The group chose to discuss:

- GPs; and,
- Social Workers.

The feedback was as follows.

### 6.1.1 FIRST PRIMARY CARE SERVICE – GPS

a) *How would you rate the service in terms of ease of access?*

*Differing views on access...*

- For some, getting an appointment was perceived as difficult. As one person put it, “*sometimes have to wait two weeks.*”
- Others seemed content that at their GP practice there were “*five different doctors... if my own GP is not available... will put me onto another*”.
- Another participant described access as “*pretty good.*”
- Another explained that his/her GP provided a very flexible service if someone was sick and unable to visit the surgery. As he/she put it “*if you’re sick... call [the surgery] between 10 and 11 [am] on the day... doctor will call you on the phone [and you just] collect your prescription.*”

b) *How would you rate the service in terms of the overall quality of the service provided, and why?*

c) *How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.*

These two topics were considered together. The group made the following points:

*Limits on when one can order repeat prescriptions...*

- One person indicated that his/her GP surgery only accepts requests for repeat prescriptions between certain times of the day. He/she wondered why it was not possible to offer this at all times of the day.

*Different views on the quality of service from GPs...*

- There were varying views on the quality of service from GPs.
- Most felt that the quality of service from GPs and GPs' attitudes were positive. One person said, *"my doctor... the service is excellent... she would go the extra mile."* Another added, *"generally treat you like a human being... relationship between doctor and patients... friendly... first name basis."* One person expressed gratitude and amazement at the interest his/her GP had shown in his/her welfare and that of his / her other patients, *"my GP visited me in hospital... had phoned to see how I was getting on... had done this with [his / her] other patients."*
- However, some people in the group felt dismissed by their GPs. One person described the general attitude of his/her GP as *"laid back... in and out in two minutes."*
- Someone else felt that locums appeared to be less interested in him/her than his/her regular GP because, in his/her experience, locums generally spent less time with patients. Another person however, took the opposite view. He/she felt that *"sometimes another doctor listens to you more."*

*Need for better attitude from receptionists...*

- Some members of the group felt that receptionists needed to adopt a more patient-centred attitude i.e. rather than seeming to protect the GP from their patients. One person felt that a GP's receptionist *"needs to be more friendly and listen to what you want."*

d) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*Better service...*

- Some members of the group felt that having status in society enabled people to get a better service. One person alleged that they knew of a GP who had accompanied an elderly woman to hospital and they suspected that the GP only did this because the woman's daughter was *"influential."*
- Others felt that *"if you know who to contact"* you would receive a better service. As one person put it, *"it's not what you read, it's who you talk to."* One member of the group claimed that when he/she was admitted to hospital he/she was given a hospital bed *"when others were waiting on trolleys."* He/she claimed this had been achieved by contacting a local councillor, who contacted his/her GP, who spoke to the relevant person in the hospital to arrange it.

e) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service at GPs:

- Have more GP practices – shorten waiting times for appointments.
- Upgrade the surgery facilities – Some members of the group felt that some of the surgeries were not easily accessible and “*some are shabby.*”
- Provide more phone numbers – The group felt that each surgery should have a variety of numbers / lines on which patients could get through. Telephoning to get an appointment seemed to be a consistent difficulty.
- Have more touch tone systems, but with humans as well – One person in the group felt that more surgeries should have the facility to allow patients to leave a message about a repeat prescription. However, he/she added that he/she would prefer if a human answered the phone before putting people through to the automated service.
- Improve receptionists’ attitude towards patients.

#### 6.1.2 SECOND PRIMARY CARE SERVICE – SOCIAL WORKERS

f) *How would you rate the service in terms of ease of access?*

*Variable...*

- A few people in the group indicated that they found it “*very difficult*” to access their social worker. Some felt that the social worker “*would only answer [calls / queries] if I badgered her*”. The same person later expressed annoyance at having to “*badger her [the social worker] at my own expense [i.e. the cost of phone calls] to get something done.*” Eventually, they decided to “*put in a complaint to [the local HSS trust] and I got a new social worker allocated.*”
- Some others indicated that their social workers were “*quite good... they will come out when they say.*”
- Another person pointed out that there seemed to be poor cover if his/her regular social worker was not available. He/she said that there was “*no cover*” when his/her social worker was off on maternity leave.
- Some felt that the level of “*access*” depended on the individual social worker. As one person put it, “*some had plenty of time to sit and listen*” whilst it seemed that others did not.

g) *How would you rate the service in terms of the overall quality of the service provided, and why?*

h) *How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.*

The group dealt with these topics together. They made the following points:

*Examples of good service quality...*

- Many felt that social workers had a “*better understanding of the jargon... services available and entitlements*” and were in a position to lever services for clients who needed them.
- One person remarked positively on the helpfulness of his/her social worker. Referring to the helpfulness of his/her social worker, one person said that, “*if they don't have the answer [to a query] they will get an answer.*” Another appreciated the amount of time his/her social worker spent helping him/her to fill out forms for social security benefits. He/she indicated that prior to this visit he/she had “*spent six weeks filling them out on my own.*” Another member of the group was grateful that “*the social worker in the hospital sorted out everything for me [them].*”

*Examples of poor service quality...*

- The general view was that there was “*a small minority who are very good [but that] they are carrying the rest.*”
- A few people felt that their social workers either did not make enough effort to help them or were not sufficiently knowledgeable about how to help them.
- One person described how, because of his/her disabilities, he/she could not use a shower. He/she had requested a bath to be installed and allegedly his/her social worker said he/she was “*being silly.*” He/she said that in the end, “*The Housing Executive offered me another flat [but that as regards their social worker] ...she didn't do much to help me.*”
- Another person told us that he/she had gone for an interview with the Northern Ireland Civil Service. He/she claimed that his/her social worker “*didn't know how to get the equipment to [help to] do the aptitude test.*” He/she alleged that he/she had to contact the Royal National Institute for the Blind (RNIB) to get the equipment.
- Another person indicated that he/she wanted to have an intercom installed but reportedly had to source it himself/herself, with no help from their social worker.

*Greater need for emotional support for some clients...*

- Some felt that social workers were too focused on the mechanical aspects of supporting their clients and not focused enough on providing the emotional support that some of their clients need. It was clear that emotional support was a priority for some clients whose lives were in a state of transition both physically and emotionally. One person felt that he/she “*couldn't tell my social worker I was unhappy going to PHAB... it was just the whole place... [and also I was] just moving out from home... only there 18 months... I felt abandoned... then [I was] passed to a part-time social worker... but when moving [house] again, I needed more support... just to listen to me... emotional support... the emotional part is the hardest part...you don't get as much support with the emotional side of things as you do with the trivial things.*”
- Some felt that social workers needed to learn to listen more closely to what their clients are telling them “*...really hear what people are saying,*” as compared with ‘cosmetic’ listening.

*Desire for continuity...*

- Some people in the group felt that they would have preferred to remain assigned to the same social worker even after they had moved house. They felt it would have provided continuity.

*Poor integration of services...*

- One member of the group felt that different parts of the overall health service “*seem to be not talking to each other.*” Referring to his/her experience of interactions between key workers such as clinical psychologists, social workers and physiotherapists, he/she felt that there were “*bits of information missing*” i.e. key aspects of his/her condition appeared not to have been communicated to the relevant key worker.

*Bad attitudes...*

- Several felt strongly that “*attitudes need to change.*”
- One person felt that the key issue was lack of empathy, “*they don't understand how you really feel... [when you have a disability] you have lost something that you really need... the emotional part is the hardest... don't get enough [emotional support].*” He/she felt this was especially at the early stages of becoming disabled / or perceiving oneself as disabled.
- Some felt it was vital that service users became more involved in the design and delivery of services. One person in the group was already mentoring others who were in a similar situation.
- One person felt that some social workers had tried to patronise him/her “*some try to imply that I am stupid.*”

i) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*Better service...*

- Some took the view that “*if you badger them [social workers] you get a better service.*”

*Lesser service...*

- Some took the view that “*if I appear to be coping, I get a lesser service... but I still need support.*” They felt that there was too much onus on the client to expose their vulnerability rather than the social worker detect this proactively, as one person explained, “*you need to say to them that you’re not coping.*”

j) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service from social workers:

- Involve service users – there was a call to engage service users in the design and delivery of services. They felt that service users would be more in tune with the feelings and practical problems a client could encounter. They also felt that service users could be especially valuable to people who were finding it difficult to cope with everyday living, they could explain “*what help is out there*” and provide hope.
- Emotional support - social workers to consider the value of emotional support to clients, not just mechanical support. Social workers to practice active listening.
- Training - social workers to receive training on how to access various aids and services.
- Desire for specialist knowledge – there was a general feeling that social workers should have an in-depth knowledge and understanding of the disabilities, and the impact those disabilities have on their clients, a better matching of knowledge and need was therefore required.

## 6.2 SECONDARY CARE SERVICES (HOSPITALS)

k) *How would you rate the service in terms of ease of access?*

*Access is good at times...*

- Most of the group felt that access to hospital services was reasonably good.
- Some felt that the waiting times were too long at A & E.

l) *How would you rate the service in terms of the overall quality of the service provided, and why?*

*Quality of service is good...*

- Many members of the group considered that the quality of hospital services was generally good.
- One person described the nurses in one of the stroke units as “*very good... brilliant... really caring... encourage you to do the things... in an attempt to get me going again.*” Participants appreciated being able to easily access any follow-up support they needed, “*I can phone direct... if my leg equipment needs adjusting... within 3 or 4 days had an appointment with Consultant... generally have to wait 3 or 4 months.*”

m) *How would you rate the attitude of health service staff based in hospitals – e.g. Consultants, nurses, theatre staff, receptionists, porters etc? How patient-friendly do you think they are?*

*Varying views on the attitudes of hospital Consultants...*

- One person indicated that, in his/her experience, Consultants were “*friendly.*” Indeed, he/she felt that some were so helpful it was “*over the top at first.*”
- Several others however, had quite different experiences. Some people reported feeling “*invisible.*” One person described how when he/she was in hospital a Consultant and his/her colleagues sat surrounding them discussing, between them, whether or not to proceed with a knee replacement. The person claimed that the Consultant and his/her colleagues made no eye contact with him/her (the participant) and did not seek to involve him/her in the discussion, “[the Consultant] *talks to them [his/her colleagues] as if you’re not there.*” He/she felt that the conversation was simply about them. On his/her own with the team of Consultants and already feeling very vulnerable, this person found the experience extremely intimidating. As he/she put it, “*I [felt as though I] couldn’t broach my concerns... they weren’t talking to me.*”
- Those consulted also felt invisible when Consultants spoke to the person who was accompanying them and not to them directly. One person expressed how

objectionable he/she found this, “*people with head injuries, they [Consultants] tend to treat us as a third person.*” He/she felt strongly that Consultants should speak directly to their patients.

*Nurses perceived to be overstretched...*

- Some people in the group felt that nursing staff were overstretched and this stress reduced their ability to carry out their duties in a helpful manner. As one person said, “*not happy with the nurses’ attitude... not helpful... overworked.*” Another felt that “*they [nurses] don’t seem to listen.*” The view was also expressed that being overstretched nurses, did not have time to give patients all of the information they were seeking. Indeed, as one person saw it, nurses gave patients “*minimal*” information.

n) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc*

*Better service...*

- Some people believed that patients receive a better service because of whom they know.
- Others felt that people received a better service once there was a clear diagnosis of their illness. One person felt as if hospital staff did not listen to a patient much at the beginning. It was as if they were waiting to determine how sick the patient was, “*... trying to work out if you are a time waster or not.*” However, he/she believed that “*once you have been diagnosed with something then they start taking more attention of you.*”
- One person also thought that the longer you stayed in hospital the better service you received. As he/she explained “*if you are there longer, you get treated better... you become part of the furniture.*” In his/her opinion, it was as if, by staying longer and by building up a relationship with the staff, that you became a real person i.e. rather than simply an anonymous person passing through the system.
- Another member of the group felt that a patient got a better service in hospital if they got a referral from a Consultant. As he/she perceived it, “*a referral from a Consultant carries more weight than a referral from a GP.*”

o) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service at hospitals:

- Make Consultants more patient-friendly – Many members of the group wished to see a change in Consultants’ attitudes towards their patients. They indicated that they wanted a “*person-friendly*” attitude. As one person said, “*they could be a*

*wee bit more friendly. I know they have to be professional but you can be professional with an attitude and professional without an attitude.” They appeared to want “someone to sit and talk... and listen... and explain”. They also wanted Consultants to “speak... in a straightforward manner”, “layman’s English”, no jargon. The members of the group emphasised that they did “not want to be talked to ‘medically’... over your head.” They also emphasised that they wished to be spoken to directly as the patient and not via any person who was accompanying them.*

### 6.3 PUBLIC HEALTH

p) *As a result of health promotion messages you may have seen in the media or information leaflets, have you changed your lifestyle in any way? If so, what was this? Was it a temporary change or a permanent one? What aspect of the message convinced you to change?*

*Some approaches seem to be effective...*

- One member of the group said that he/she stopped smoking because of a combination of the TV campaign on stop smoking, plus the fact that one of his/her parents had died from cancer. As he/she explained, *“I seen the way it made your lungs.”*

*Others more affected by family health history and events...*

- Another member of the group said that he/she had stopped smoking and had changed over to a healthy diet, not because of the stop smoking campaign but because three of his/her uncles had died of heart disease in the same year.

*Need more health promotion that takes account of disability...*

- One person felt that it was laudable for health promotion to target obesity and to encourage people to change their sedentary lifestyles, however, he/she added, *“they [health promotion campaigns] forget that some people can’t do that... [consequently, people with disabilities and mobility problems] feel like a minority.”* They felt that the mainstream health promotion campaigns, *“...never seem to deal with people with disabilities.”* They considered that health promotion should do more to partner with various organisations to encourage people with disabilities to, for example, get involved in sport.

#### 4 GENERAL ISSUES

q) *What do you feel is the most important problem facing health and social services in Northern Ireland today and why? And can you make one suggestion as to how this problem should be tackled or resolved?*

*Variety of issues...*

- Obesity – The group felt that obesity “and the illnesses that come along with obesity” needed to be addressed.
- Drug misuse – Many felt that drug misuse was commonplace. One person said that they would be “afraid to leave drinks” in a bar in case someone would put drugs in them.
- Alcohol abuse – Several members of the group felt that this was a major issue. They perceived it would be a difficult challenge because alcohol is so closely linked with “the way we socialise.”

r) *Excluding prescription charges, have you paid for any health or social care related service directly from your own money in the last 12 months (i.e. not including through a private medical insurance scheme)? Why did you choose to pay for this health or social care service?*

*Variety of services...*

- One person had paid privately for the birth of his/her second baby. The first baby had been still born. The person concerned said, “I was taking no chances.”
- Another person had paid for cleaning services. He/she explained that after getting out of hospital, the home help did the ironing but was not allowed to do the cleaning. Consequently, he/she paid the home help privately to do cleaning.
- Others in the group indicated that they had bought aids and appliances using their own money because the waiting list for these items was, in their view, too long.

s) *How effective do you think Health and Social Services is in resolving complaints?*

*Mixed views...*

- Some people indicated that they got a “satisfactory” response to the complaint they made.
- However, one person expressed frustration at having to write so many letters. He/she reportedly did not actually speak to anyone and no-one opted to speak to him/her. Instead, the entire interaction was done by letter. He/she felt that it

should be possible to speak to a person to resolve matters more readily. He/she found the process cumbersome and a poor vehicle for communication. As he/she put it, “*you can’t describe how you feel on a piece of paper.*”

- Another person felt that getting an issue resolved could simply be hit and miss sometimes. He/she reported having waited two years to be seen by a certain member of the health service. He/she was puzzled by the delay and rang and spoke directly to this person’s receptionist. He/she claimed that an appointment was obtained for the following week but added, “*it was just luck, good luck.*”

## 7. TRAVELLERS

<b>FOCUS GROUP:</b>	TRAVELLERS
<b>VENUE:</b>	COMMUNITY HOUSE, OMAGH
<b>DATE</b>	15 <sup>th</sup> APRIL 2004
<b>NUMBER OF PARTICIPANTS:</b>	9

Profile of Participants			
		Number	%
<b>Sex</b>	Male	5	56
	Female	4	44
<b>Age</b>	Under 18	-	-
	18-24	1	11
	25-44	6	67
	45-64	2	22
	65-74	-	-
	75+	-	-
	No Answer	-	-
<b>Disability</b>	Yes	1	11
	No	8	89
	No Answer	-	-
<b>Dependent Children</b>	Yes	7	78
	No	2	22
	No Answer	-	-
<b>Other Caring Responsibilities</b>	Yes	5	56
	No	4	44
	No Answer	-	-

## 7.1 PRIMARY CARE SERVICES

The group chose to discuss:

- GPs; and,
- Dentists.

The feedback was as follows.

### 7.1.1 FIRST PRIMARY CARE SERVICE – GP

a) *How would you rate the service in terms of ease of access?*

*Mixed views on access...*

- Those consulted felt that it was difficult to get an appointment with their regular GP. As one person put it, “*you have to wait one or two weeks... you wouldn’t need to be dying half the time!*”
- However, they acknowledged that it was easy to get an appointment with the “*emergency doctor.*” Access in this regard was satisfactory.

b) *How would you rate the service in terms of the overall quality of the service provided, and why?*

*Service quality good...*

- Service quality was commended. Most felt that in the majority of cases, GPs were prepared to “*sit down and listen*” and take time with their patients.

c) *How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.*

*Good attitude...*

- All of those consulted described GPs as having a positive, non-patronising attitude, “*very friendly... don’t talk down to you.*”

d) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*Same service for all...*

- Those consulted believed that the service was available equally to all as illustrated by the following comments,
  - “[everyone] *pretty much get[s] the same*”; and,
  - “*all get the same service.*”

**e) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)***

Those consulted made the following suggestions to improve the service provided by GPs:

- The main issue related to waiting times for appointments. As one person put it, there should be “*more doctors and then you wouldn’t have as long to wait... you would be seen quicker.*”

#### 7.1.2 SECOND PRIMARY CARE SERVICE – DENTIST

**f) *How would you rate the service in terms of ease of access?***

*Varied views on access...*

- Some people thought that it took too long to get an appointment “*you have to wait about a month.*”
- Others felt that in the case of an emergency that access was good, “*you get seen the same day.*”
- One person commented that at his/her dentist the physical access was very straightforward, “*no stairs.*”

**g) *How would you rate the service in terms of the overall quality of the service provided, and why?***

*Generally good but apparently different in different locations...*

- Most felt that, generally speaking, the service is “*good enough.*”
- A few people gave us to understand that there were different regimes for charging for services in different places. One person alleged that in Omagh a dentist would charge typically £250 for a brace whereas a dentist in Dungannon would carry out the same work under the NHS for free.
- One person felt that the quality of the service was poor because they perceived that dentists did not strive hard enough to save a tooth, “*too quick to take teeth out.*”

*h) How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.*

*Generally thought to be good...*

- Most of those consulted felt that the attitude of dentists was generally good.
- However, one person described how one dentist had been aggressive with a traveller who had requested an emergency appointment. He/she felt simply that, “*he must have had a bad day.*”

*i) Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*All the same...*

- Those consulted felt that everyone gets the same service from their dentist.

*j) In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service at dentists:

- All services should be free to those on benefits. One person felt that, “*if you are on Income Support you should be entitled to these services*” i.e. without any charge. It did not appear to make sense why “*teeth get pulled and filled for nothing*” yet people have to pay for to have braces fitted or broken teeth repaired.

## **7.2 SECONDARY CARE SERVICES (HOSPITALS)**

*k) How would you rate the service in terms of ease of access?*

*Access deemed to be good for now...*

- Those consulted felt that access was good at present i.e. with Omagh Hospital being nearby. However, many expressed concern about the threatened closure of Omagh Hospital and the consequent prospect of having to go to Enniskillen or Craigavon for treatment. Neither of these locations was considered easily accessible.

l) *How would you rate the service in terms of the overall quality of the service provided, and why?*

*Varied opinion...*

- Most thought that the quality of the service was good. One person described it as “*first class.*”
- However, a few expressed dissatisfaction with, what they perceived as, the long waits in accident and emergency. One person felt that there was not enough staff on duty in accident and emergency. He/she also felt that the staff were “*over worked.*”

m) *How would you rate the attitude of health service staff based in hospitals – e.g. Consultants, nurses, theatre staff, receptionists, porters etc? How patient-friendly do you think they are?*

*Perceived prejudice by some staff...*

- Some members of the group felt that a minority of the nursing staff were prejudiced against them. One person described the way in which some nurses dealt with him/her by saying, “*they look at you as though you shouldn’t be there.*” Another person, who had attended casualty several times in quick succession alleged that a nurse in accident and emergency addressed him/her in an irritated voice saying, “*Oh no! Not you again! ...her [the nurse’s] face was twisted.*” He/she believed that the same nurse would not have addressed him/her in that manner had he/she had not been a traveller. Another person alleged that one nurse had treated a traveller child quite roughly when taking out the child’s stitches. Again, this person felt that the child would have been treated more gently if he/she had not been a traveller. Overall, however, they felt that attitudes were generally good and that experiences such as those above were exceptional, “*...comes down to individual personalities.*”

n) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, males or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*Everyone gets the same service...*

- With the exception of a few examples of what was perceived as prejudiced behaviour, the participants consulted felt that, “*...everybody gets pretty much the same service.*”

o) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service at hospitals:

- Have more nurses and doctors.
- Train staff so that they do not have a prejudiced attitude against travellers.
- “Fix up” whatever hospitals already exist and keep them up to date rather than spending money on new ones (i.e. a reference to the threatened closure of Omagh Hospital).
- Make provision for children to stay overnight in Omagh hospital. (We were given to understand that, at present, Omagh Hospital cannot accommodate children overnight, they have to be taken to Enniskillen).
- Have a maternity ward in Omagh Hospital.

### 7.3 PUBLIC HEALTH

p) *As a result of health promotion messages you may have seen in the media or information leaflets, have you changed your lifestyle in any way? If so, what was this? Was it a temporary change or a permanent one? What aspect of the message convinced you to change?*

*TV adverts on stopping smoking...*

- These were generally thought to have no effect.
- Largely the adverts tend to be deliberately ignored by smokers. As one person put it, “...if it [the advert] comes on in the house, I just turn it off.”
- Some people found the TV adverts showing the build up of contaminants “disgusting” and therefore would not watch it.
- Many were convinced that media promotion was pointless and that it was really up to an individual whether or not they decided to give up smoking. One person commented, “...if they are going to do it [give up smoking] they will do it... [but] not because of the ad.”
- A few people felt that “some people will be affected by them [the adverts].” However, they did not think that they themselves would.

*Leaflets also thought to be pointless...*

- Generally the group felt that leaflet drops were a waste of time too. They did not appear to be an effective way to deliver a lasting message to people. As one person said, “if they [health promotion leaflets] come through the door you look at it [the implication was briefly] and then bin it”

#### 4 GENERAL ISSUES

q) *What do you feel is the most important problem facing health and social services in Northern Ireland today and why? And can you make one suggestion as to how this problem should be tackled or resolved?*

*Variety of issues...*

- Those consulted listed a range of issues which they felt health and social services needed to address, namely:
  - More nurses and doctors in hospitals;
  - The issues of drinking and drug misuse – especially amongst younger people;
  - The long waiting times to see specialists – three months or more regarded as far too long.
  - The threat of the closure of Omagh Hospital – perceived as a vital resource in the local area. One person who was concerned about this issue remarked, “*there will be no hospitals if they keep closing them all down*”;
  - The use of medical and nursing staff from foreign countries – some of those consulted alleged that they found it “*very hard to understand*” some of the accents. Another person commented, “*good enough doctors but you can’t understand them*”;
  - The quality of hospital food. Most believed it needed to significantly improve.

r) *Excluding prescription charges, have you paid for any health or social care related service directly from your own money in the last 12 months (i.e. not including through a private medical insurance scheme)? Why did you choose to pay for this health or social care service?*

*Some services had been paid for privately...*

- One person indicated he/she paid so that his/her grandmother could have a hip operation done. He/she said that his/her grandmother was seen within a week and that if she had waited to have the operation done on the NHS she would have had to wait two years.
- Another person said that his/her mother, after coming out of hospital, paid for the services of a cleaner when it became clear that the home help that had been allocated to her would not do cleaning.

s) *How effective do you think Health and Social Services is in resolving complaints?*

*No experience of making formal complaints...*

- All of those consulted said that they “*would not complain.*”
- Fundamentally, they felt it was futile. They had no confidence that the system would try to support their complaint / try to address the issues they would raise. As one person put it, “*I don’t think they would listen to you anyway... what is the point?*”

## 8. OLDER PEOPLE IN A RURAL AREA

<b>FOCUS GROUP:</b>	OLDER PEOPLE IN A RURAL AREA
<b>VENUE:</b>	GORTMORE HOUSE, MAGUIRESBRIDGE, CO FERMANAGH
<b>DATE</b>	20 <sup>th</sup> APRIL 2004
<b>NUMBER OF PARTICIPANTS:</b>	8

Profile of Participants			
		Number	%
<b>Sex</b>	Male		
	Female	8	100%
<b>Age</b>	Under 18	-	-
	18-24	-	-
	25-44	-	-
	45-64	2	25%
	65-74	6	75%
	75+	-	-
	No Answer	-	-
<b>Disability</b>	Yes	3	38%
	No	4	50%
	No Answer	1	13%
<b>Dependent Children</b>	Yes	1	13%
	No	7	88%
	No Answer	-	-
<b>Other Caring Responsibilities</b>	Yes	3	38%
	No	4	50%
	No Answer	1	13%

## 8.1 PRIMARY CARE SERVICES

The group chose to discuss:

- GPs; and,
- Home Helps.

The feedback was as follows.

### 8.1.1 FIRST PRIMARY CARE SERVICE – GP

a) *How would you rate the service in terms of ease of access?*

*Access perceived as difficult...*

- Those consulted felt that it was very difficult to get to see a GP at the weekend or out of hours.

b) *How would you rate the service in terms of the overall quality of the service provided, and why?*

*Generally good quality...*

- Many felt that in the main the quality of service, when it could be accessed, was good, “*could not be beaten mostly.*”

*Poor quality of service from out of hours doctors...*

- In general, those consulted thought it was unsatisfactory that the Doctor on call came to visit without having notes about the patient. They felt that it should be possible to access someone’s medical information from a central point via their medical card number.
- In short, they felt that because of the difficulties in accessing patient information, “*they [locums and out of hours doctors] don’t know anything about you when you go in unless it’s your own GP.*”

c) *How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.*

These topics were considered together. The group made the following points:

*Mixed views on attitudes and quality of service...*

- A few people thought that in terms of positive attitude and quality of service, their GPs “*couldn’t be beaten.*”
- Some others, however, felt that GPs attitude and the quality of service they provide “*leave a lot to be desired sometimes.*”
- A few felt that some GPs had a bad attitude. They perceived that at times such GPs were not patient. They also felt that some GPs were slow to diagnose a patient. We were given a few instances where allegedly GPs were slow to diagnose serious illnesses.
- One person gave an example of where she perceived a GP had been sarcastic to a patient. She claimed that a patient who was dying of cancer, who was, according to her, losing hair and nails, attended his/her GP and the GP allegedly said, “*are you down for a sick note?*”. She felt this sarcasm was both callous and inappropriate.
- Others commented on what they perceived as a dismissive attitude / tone of some GPs. One person gave an example of where her husband had fallen off a roof. She claimed her husband had broken his arm. She called their GP who allegedly said, “*it’s not my domain... take him to casualty.*” Whilst this may have been factually correct, she objected to the unfeeling manner / tone.
- A few others thought that it was simply bad manners for a GP to be “*updating his computer*” before attending to his patient. As one person put it, “*if you are in a lot of pain*” you want to have the GPs’s undivided attention. To her it seemed as if the computer was more important.
- One person disliked the patronising attitude of a GP she had attended. She told us that the GP had described the symptoms of her illness in terms of parts of a car and what was going wrong. She felt as though the GP thought she was stupid.

d) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*Better service...*

- Some felt that those who had the “*courage to stand up and ask for service*” were likely to get a better service.

e) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service at GPs:

- Have a central system whereby medical records can be retrieved readily.

- Conduct surveys in GP practices to let GPs know what their patients think about the quality of the service they provide. The views of patients should be taken on board in the development of future services.
- Anyone who is house bound should receive a visit from the GP once a month. One person in the group understood that in the past GPs were required to visit the over 80's. She felt it was a loss that this no longer happens.

#### 8.1.2 SECOND PRIMARY CARE SERVICE – HOME HELPS

*f) How would you rate the service in terms of ease of access?*

*Perceived as very difficult to access...*

- Most of those consulted felt that home helps were *“impossible to get.”*
- One person felt the system of being assigned a home help was not reliable. She claimed that she had contacted Social Services about a home help for an elderly neighbour who was very ill. She claimed that no home help came and yet allegedly Social Services claimed they had assigned and sent a home help to this person.

*g) How would you rate the service in terms of the overall quality of the service provided, and why?*

*Poor, unrealistic time allowances...*

- Many believed that the *“hours are too short.”* As one person said, *“what good’s half an hour?”*
- One person who had been a home help themselves said, *“any less [than an hour] is no good... it’s impossible to get washed up... you were busy in that hour.”*
- Another person who had been a home help explained how completely unrealistic the time allowances were in her view, *“[you have] from 9.00 to 9.30... you need 5 minutes to speak to the person(!)... by the time I washed, shaved him and got him dressed ... and I have to be at the next house by 9.30... it’s not possible without a broomstick!”*
- Another person remarked that, because of mobility problems, some clients could take a few minutes before they can get to the door to let the home help in. When the time allowance is so meagre in the first place, this makes a big difference.
- The meagre amount of time allowed appears to be squeezed further by the requirement to travel from client to client in such short timescales. One person claimed that, *“some [home helps] can’t stay the full amount of time... they have to travel... they [management] don’t seem to factor this in.”*

*Not enough home helps...*

- There was a general feeling that the service was now in very short supply. As one person said, “*they [Social Services] have cut back on the service.*”

*Poor remuneration...*

- Others commented on the small number of people coming forward to be a home help - “*there aren’t enough carers... the pay would not entice them to come out.*”
- There was general agreement with the notion that, “*there is no travel time [built into the home help schedule] or expenses... it’s crazy!*” and with the idea that, “*the wages do not entice anyone.*”
- Another person commented on the rising cost of car insurance and MOT and felt it was unfair that given most home helps needed a car to do their job that there was seemingly no account taken of this in the overall wages for home helps.

*Not enough cover when regular home help not available...*

- There was a general feeling that there was virtually no cover in place when a home help was not available. As one person put it, “*there is no spare wheel.*”
- One person claimed to know of a situation where, due to a home help having had an accident, the client was without a home help for two weeks.
- One person felt that, when a home help is not available, there was insufficient cognisance taken of the age and abilities of the client. She claimed that a local person aged 92 was without a home help for four days. She also alleged that this person “*can’t dress or put on a coat without help*”. Without the home help, “*it was down to the neighbours to step in and cook a meal.*”
- The general feeling within the group was that the service was firstly so difficult to access and secondly so unreliable if the client’s regular home help was not available that most people felt they would not wish to be depending on it. In the words of one person, “*I’m glad I’ve got my family.*”

*Poor communication and poor co-ordination...*

- Several members of the group criticised what they perceived as failings of management to operate the service effectively. A few people gave examples of what they perceived as “*wasted resources... could have two people [home helps] at the same place [client]*” when only one was needed. Others gave examples of where it seemed to them there had been a “*breakdown in communication*” by management and a home help that had been supposed to cover client X had failed to do so because allegedly they had not been told.

*Apparently inadequate training...*

- A few members of the group commented on what they saw as inadequacies in the way in which home helps are trained. It seemed to them that some home helps are trained in the use of certain aids etc and some are not. The rationale for such differences was not evident.

*Apparent differences in what home helps do...*

- We heard about some apparent inconsistencies in what home helps are allowed to do. One person claimed, “*some [home helps] help sort tablets and make sure [the] old person has their medication, others don’t.*”

*Insurance claims has reduced the service available...*

- A few people at the group felt that the level of insurance claims from home helps and the litigious society in which we live has resulted in the service offering being seriously curtailed, “*it all has to do with insurance... our society has done this.*”

*h) How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.*

*Variety of views...*

- “*Some are brilliant... some are quite nasty.*” Most people in the group felt frustrated at the very limited set of services a home help could offer. They felt it came across as quite negative (“*nasty*”) when a home help is asked to do “*something slightly outside their remit*” and they reply, “*I can’t do this.*”
- A few members of the group claimed, “*some of the good ones do extra in their own time.*”
- Some others felt that many home helps did not demonstrate a truly caring attitude, the work had become no more than a job. As one person said, “*some just do it for the money and they don’t really care.*”
- Others acknowledged that home helps are human too and pointed out that stress effects the way the home helps come across and perform their duties. Many appreciated that home helps have a lot to do in the time allocated, “*there is no allowance for flexibility.*” They felt that this pressure would inevitably affect the quality of the relationship with the client.
- One person felt that the service was so far stretched, and the focus appeared to be on getting tasks done rather than providing care that some home helps no longer had time even to simply ask their clients how they were. The group felt it was fundamental to ask a client how he/she was feeling.

i) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, males or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*Same service...*

- Some people felt that clients get a better service if the home help is kind and wants to help. The importance of a genuinely caring attitude was stressed in several ways throughout the session. In the words of one person, *“I think it is very important [for a home help] to have a liking for people, and it is the same for nurses and things like that.”*

j) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service from home helps:

- Put more focus on a caring attitude – it was considered to be fundamental that the home help has time to ask the client how he/she is feeling. The focus should be on the care of the client not exclusively on the tasks.
- Allow home helps to do more routine tasks - for example, one person in the group considered a situation where a client had spilt a cup of tea. To her it would make sense for a home help to be allowed to clean this up. However, a home help would not be allowed to do this under the present set up. She felt it was ludicrous to allow something as simple as this to be overlooked and to perhaps create a hazard for an elderly person. She added, *“common sense would be a good thing!”*
- Provide or partner with other support services – one person felt that if a home help was not allowed to do cleaning that Social Services should seek a partner who could provide this. She contended that if a person could not dress himself or herself, he/she was unlikely to be well enough to do his/her own laundry. She felt that each case should be assessed individually but that the principle of partnership working to provide a holistic service, relative to the clients’ needs should be considered.
- Monitor client satisfaction – the group agreed that, even at a personal level, there was no guarantee that home help and client would “gel.” However, the group felt it was vital that a client felt comfortable with someone who was providing them with personal care. They felt that the service *“should be monitored by a social worker.”* Some suggested that a review should take place every six months. Others felt that once a month was more appropriate. They felt that a client should be asked explicitly if they are satisfied and any areas of dissatisfaction noted and actioned. One person contended that this was especially important for an elderly person living alone. She felt that such people could potentially dwell on incidents if they had no-one to turn to. As one person said, *“a home help may have upset the [client] ...older people have all day to analyse every wee detail.”*

- Have a probationary period – one person suggested that there should be a probationary period of six months and that a client's satisfaction with their home help should be carefully monitored during this period. She felt that a home help should only be appointed to a client after he/she had successfully passed through the probationary period.
- Provide more hours per client – this would enable more tasks to be done and provide time for a meaningful home help / client relationship to develop.
- Allocate realistic amounts of time for travel – So that home helps can carry out all their tasks without having to cut short their time with one client to travel to the next.
- Provide a travel allowance – Give home helps money to cover their travel expenses.
- Match the training to the client's needs and equipment – Many felt that a home help should be specifically trained to use whatever equipment (e.g. hoists etc) a client needed to use.

## 2 SECONDARY CARE SERVICES (HOSPITALS)

*k) How would you rate the service in terms of ease of access?*

*Seems to depend on GP...*

- Many felt that one's access to a hospital depended on a GP and on "how much they insist you go."

*l) How would you rate the service in terms of the overall quality of the service provided, and why?*

*Generally thought to be poor...*

- One person felt that the quality of care was good, "they [hospital staff] kept me alive."
- Several people gave examples of situations where they perceived the quality of care was poor.
- One person alleged that someone she knew had been in and out of the local hospital for weeks and then was finally referred to a Belfast based hospital for an operation. The patient died there. The Consultant in the Belfast based hospital was alleged to have said that the patient would have been alive had he/she been referred earlier.
- There was a further example given of follow-up documentation allegedly taking an inordinate amount of time. One person described how a patient with suspected

angina went to hospital and was discharged. This particular person was supposed to have been given a letter to follow up. According to the person in our focus group, the patient had been told that the letter had been dictated but not typed. Ten weeks had passed between the person being discharged and the most recent enquiry made about the letter.

- Summing up her view of the quality of hospital services overall, one person said “*It stinks!*”

*Concerns about the ambulance service...*

- One woman told us how she felt that the directions that she gave to the ambulance service were ignored. When her husband was seriously ill, her GP advised her to call an ambulance. She told us that she did this and “*gave specific directions*” to the person who took her call. Before the ambulance arrived, the driver phoned her and seemed to be “*looking for a telephone box*” presumably as a landmark. She was adamant that she had not mentioned a phone box in her set of directions and therefore felt that the person who had taken her call had not passed on her directions. In her opinion, she had advised on the fastest, best road to reach her house. Again, she claimed she was dismayed to find that the ambulance was taking what she described as “*the roughest roads in Fermanagh*” to get back to the hospital, and, she alleged that the ambulance had to slow down because of the roughness of the roads. She claims she asked the driver to take what she believed was a faster and smoother route. She alleged that he ignored her advice. She believed that had they listened to her directions to and from the hospital, and as she believed, saved time, that it “*would not have had the fatal outcome that it did*” for her husband. She contended that she, and not the controller “*based in Derry*”, knew the local terrain. She concluded, “*the ambulance men don’t know the roads.*”

m) *How would you rate the attitude of health service staff based in hospitals – e.g. Consultants, nurses, theatre staff, receptionists, porters etc? How patient-friendly do you think they are?*

*Nurses are very good...*

- One person felt that the “*coronary care ... nurses are marvellous.*”

*Very poor attitude of some Consultants...*

- The experience of many people in the group was that Consultants had a generally bad attitude towards their patients.
- Consultants’ attitudes were described as “*anything but civil*”, “*bedside manner is abominable!*”, “*very brusque attitude*” and “*horrendous... cheeky.*”
- Many perceived that Consultants acted as though they were somehow infallible and seemed unable to apologise for any mistakes. As one person put it, “*...you*

*would think more of them [Consultants] if they admitted they got it wrong and said sorry.”*

- However, a few accepted that the litigious society in which we live does not help and acknowledged that Consultants may be afraid to admit they have done something wrong in case a patient and / or a family member sues them.

*Bad attitude of other hospital staff...*

- One person described how angry she became with staff in an X-ray department. This person had brought a relative into hospital to have a fracture set but he/she was utterly convinced that the bones had not been set correctly. Allegedly, the hospital staff would not take the plaster off and the X-ray department would not let this person see the X-rays (to confirm whether or not it had been set correctly). Eventually, this individual phoned the fracture clinic in (in Londonderry) and took the patient there. The fracture did need re-setting. However, she felt that the disruption for the patient could have been entirely avoided if the staff at the local hospital had been reasonable.

n) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old, young etc, males/female etc, affluent or disadvantaged, disabled / non-disabled etc*

These two topics were considered together.

*Better Service...*

- Those consulted felt that younger people were more assertive and consequently were more likely to get a better service.

*Lesser service...*

- Those consulted felt that elderly people were at risk of receiving a lesser service. They were concerned about the attitude of hospital staff towards older people. In the words of one person, *“there seems to be an attitude in hospitals if you are over 50... ‘Move over and leave room for the young ones.’* The group felt that hospitals want old people to go home to free up beds. They felt that they were perceived by hospitals as *“being in the way.”*
- They also felt that older people were less likely to be assertive and that *“medical staff take advantage of older people’s complacency”* and consequently older people were at risk of receiving a lesser service.
- One person claimed that they had been sent for a chest X-ray only to be told by one of the radiographers that at that hospital *“over 60s [were] not getting chest-rays.”* Allegedly, the person was later told by hospital staff that they could have a chest X-ray but only if they agreed to have a general anaesthetic. Having a heart condition, she was not willing to consent to this. However, she claimed *“the Consultant tried to talk me into it.”* She felt that this policy amounts to ageism.

*o) In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service at hospitals:

- Decide and make public what the new configuration of hospitals is to be - one person felt that the current uncertainty about hospitals is placing a great strain on staff and this is rubbing off on patient care. One person, referring to her small local hospital said, *“for a small local hospital it has lost its personality.”* There was an acknowledgement that many staff in the local hospital are on temporary contracts and they felt that this was *“not conducive to good staff attitudes... staff should get permanent work.”*
- Improve hospital hygiene – the cleanliness of hospitals was described as *“horrendous.”* The group criticised what they perceived as the poor standard of cleaning provided by contract cleaners. One person believed that the work which was done was very scanty and superficial and well below what he/she would have regarded as adequate for a hospital, *“they [contract cleaners] come in and rub things over and go out.”* Many believed that in terms of a regime, hospitals should *“go back to the days when you had a matron”*. They perceived that the standards of cleanliness were significantly better under this arrangement.
- Reduce paperwork for nurses – there was a general feeling that nurses are too tied up with paper work these days and that this had reduced the time available for direct patient care.

### 8.3 PUBLIC HEALTH

*p) As a result of health promotion messages you may have seen in the media or information leaflets, have you changed your lifestyle in any way? If so, what was this? Was it a temporary change or a permanent one? What aspect of the message convinced you to change?*

*Mixed views ...*

- There were mixed views about the value of health promotion campaigns.
- A few felt that health promotion message have *“some impact on some people.”*
- One member of the group said that she went walking because of the TV advertisements (health promotion). She stated that, the adverts helped to underline the importance of looking after your health.
- Others indicated that they had learned that things they might have thought of as forbidden foods were actually good for health in moderation, for example, chocolate and red wine.

- Some felt that the “*Stop Smoking*” TV adverts might stop young people from starting smoking.

#### 8.4 GENERAL ISSUES

q) *What do you feel is the most important problem facing health and social services in Northern Ireland today and why? And can you make one suggestion as to how this problem should be tackled or resolved?*

*Variety of issues...*

- Charges for health care - there was a general discontent at charges for health care services and the apparent unfairness of the way in which charges were levied. It seemed to some that “*people who have never worked [get] everything handed to them on a plate*” and yet others, “*if I go to the dentists or optician, I have to pay for treatment... that galls me to the bone.*”
- Poor attitude to older people – One of the members of the group sometimes felt that the government did not make easy for older people to access services. In fact, they were inclined to believe that the “*Government hope you are going to die before you need it*” i.e. the health service.
- Immune system of this generation – One person remarked how today “*every child from two [years old] gets vaccinated... what [level of] immunity will the next generation have?*”
- Increase in the prevalence of allergies – Some members of the group were concerned about the rise in the prevalence of allergies, for example, to peanuts, dairy products etc. They wondered if this would continue to rise in the future.
- Modern methods of food production – The group expressed concern about the possible negative effects of artificial fertilizers, pesticides and GM crops on the health of present and future generations.

r) *Excluding prescription charges, have you paid for any health or social care related service directly from your own money in the last 12 months (i.e. and not include through a private medical insurance scheme)? Why did you choose to pay for this health or social care service?*

*Paid privately for a range of services...*

- One person indicated that she had paid privately for chiropody. The person concerned remarked that, in her opinion, there was a lack of chiropody in rural areas.
- Another person with arthritis paid £7k to have an operation done privately. She did not want to have to spend four years on a waiting list.
- Another member of the group indicated that she pays privately to have her heart checked each year.

s) *How effective do you think Health and Social Services is in resolving complaints?*

*Many don't bother to complain...*

- Most people felt that complaining was “a lot of hassle... most people don't bother.”
- Some felt they had just reason for complaining but did not follow through because the patient did not wish to proceed with it for their own reasons. One person said that she was going to complain on behalf of a family member whom she felt had received a poor service from the hospital. However, the person concerned did not wish to have the matter pursued and so she abandoned it.

## 9. CARERS

<b>FOCUS GROUP:</b>	CARERS
<b>VENUE:</b>	BANBRIDGE ENTERPRISE CENTRE BANBRIDGE
<b>DATE:</b>	21 <sup>st</sup> APRIL 2004
<b>NUMBER OF PARTICIPANTS:</b>	9

Profile of Participants			
		Number	%
<b>Sex</b>	Male	2	20
	Female	7	70
<b>Age</b>	Under 18	-	-
	18-24	-	-
	25-44	2	20
	45-64	6	60
	65-74	1	10
	75+	1	10
	No Answer	-	-
<b>Disability</b>	Yes	5	50
	No	4	40
	No Answer	1	10
<b>Dependent Children</b>	Yes	2	70
	No	7	20
	No Answer	1	10
<b>Other Caring Responsibilities</b>	Yes	10	100
	No	-	-
	No Answer	-	-

## 9.1 PRIMARY CARE SERVICES

The group chose to discuss:

- *Day Centres, and,*
- *Home Helps.*

The feedback was as follows.

### 9.1.1 FIRST PRIMARY CARE SERVICE – DAY CENTRES

#### a) *How would you rate the service in terms of ease of access?*

*Being allocated a place seems easier for some than others...*

- Some people commented, *“in the Portadown area, you are on a waiting list... not too hard to get a place.”*
- It seemed that places were easier to access for older people, people with physical health problems or people with learning disabilities. One person said that after his/her mother had lost both her legs, *“she was considered an urgent case... waited three months... [she now goes] one day a week.”* The three-month wait, whilst not ideal, was thought to be reasonable. Another person whose wife had motor-neurone disease indicated that she had been allocated a place in six weeks. This too was considered this to be reasonable. Some therefore took the view that *“the system works well”*.
- However, accessing a place for an individual with significant behavioural problems seemed more difficult for some. One person, who had a young son with behavioural problems and who could be violent, was allegedly told by the local health trust that his/her son would need one-to-one care in a day centre. However, the health trust had allegedly indicated that they would need more funding to provide such one-to-one care and it would be five years from now until they could say whether or not the funding would be available. The young person’s mother, who is disabled herself, was extremely concerned that her son would be *“taken off me [her] if he is not given the care”* in the day centre.

*Insufficient service available at certain times of the year...*

- Some people felt that there needed to be more care available at certain times of the year, especially in situations where carers’ only get respite when the person they care for is at the day centre. One person indicated that a local day centre was closed for two weeks at Christmas and he/she knew of a carer who was not going to get a break at all for this period.

*Transport generally provided...*

- Many of those who attend a day centre get there by bus. We were told, “*the bus service works quite well in Portadown.*” Others indicated that a mini-bus service operated (in Banbridge). Whilst some took the view that the transport service was “*very good*” there were a few who contended that the buses were unavailable too often. They claimed that carers were frequently given too little notice (see below under the question about service quality).

*Time required to travel to and from the Centre...*

- Many of the carers we consulted were concerned about, what they saw as, excessively long periods spent travelling to and from the day centre and further afield.
- Some gave examples of the typical length of time their relatives spent getting to and from their respective centres each day:

“*around three and [a] half hours... the nearest centre is in Downpatrick*”;

“*[about two and a half hours a day] one and three quarters one way and the same in the evening... nature of the terrain [rural] ...lots of pick ups*”;

“*[about three hours each day] some mornings my husband is picked up at 8.30 [am] and he gets there about 10 [am].*”

- It seemed that there was a fixed system of first on / last off. In effect, this meant that there was no option for someone with a typically long journey time to experience a short spell travelling.
- One person pointed out that the travel does not end at the centre, sometimes “*they [the staff] decide to go out for the day [with the clients] and then they [everyone] are off on another bus!*”
- Some felt that these journey times were unavoidable, “*we have to appreciate we are in a rural area.*”
- Others felt that clients should be offered the choice about whether or not they want to go out on trips.

*Steps cause problems for some people...*

- One person explained that his/her mother, who had “*a heart problem*”, attended a day centre. However, he/she considered “*access to it is difficult... there is steps... the bus leaves her [the participants’s mother] to the door... but the steps*” created difficulties.

*Lack of wheelchair access...*

- One person alleged that the day centre, which his/her mother attended, did not have wheelchair access.

b) *How would you rate the service in terms of the overall quality of the service provided, and why?*

*A few perceived that the transport service was good.*

- *“I find the transport service very good and I hope they continue with that.”*
- *“The bus service works well picking people up and dropping them off at the door”.*

*However, most had problems with the transport service...*

Several people considered that the service was not reliable and commented on what they saw as major deficits in the system.

*Too often buses are not operating...*

- One person described what he/she perceived as a very inconsiderate process of informing service users that there would be no bus available on a particular day, *“you get no notice if the bus isn’t coming... you get a phone call first thing in the morning”*. He/she felt that this was not sufficiently far in advance to enable people to make alternative arrangements.
- One person also said, *“the buses are so old... they break down frequently”*, he/she felt that the explanations offered were feeble, *“can’t come when it’s snowy... or icy... or ‘the door doesn’t work properly!’”*

*No back up service...*

- It seemed to one person as though there was no backup service in operation if the regular buses were not available. No alternative arrangements were offered, *“the person just doesn’t get to the day centre.”* He/she considered this to be unacceptable.

*No service available during the day...*

- One person told us, *“if they [the client / day centre user] get sick... there are no drivers... if you don’t drive you have to ring a taxi and use your own money to pay for it [there and back] and what if you don’t have money?”* The person making this comment was on benefits.

*Buses sometime returning early without warning. Drivers allegedly not checking if anyone home...*

- One woman indicated that she had problems at times with the mini-bus service returning a relative home earlier than usual. She described how on one occasion,

the bus had arrived earlier than usual and she was not at home. The house was empty. She said, “no-one lets you know they [the bus] are coming home early”. Her daughter, who had special needs and was also epileptic, realised that there was no-one at home and asked the driver to drop her off with her father a few miles away. Allegedly, the bus driver told her that he would not have time to drive to take her to her father’s. Just at that point, she herself, by chance, arrived home. She claimed that the bus driver was allowing her daughter to get off the bus alone. She said that she was dismayed that the bus driver did not wait to check if there was anyone home.

- Another person described a situation where a Down’s Syndrome child, living in a rural area was left home by a day centre bus driver. Allegedly, the child’s mother had died during the day and apparently it was not until someone came visiting later on that anyone realised what had happened.

*Some drivers do not appear to be properly trained to use equipment...*

- One person alleged that one of the bus drivers had said that he/she could not take his/her relative on board the bus that day because a certain piece of equipment (chair lift) was not working. The person claimed that they could see that the piece of equipment had instructions on it that explained how to be operated manually in the event of an electronic failure. He/she also asserted that the bus driver did not appear to know how to do this and both of them had to work together, helping each other, before the piece of equipment could be operated manually. Our focus group member felt that all drivers should have been trained to operate emergency equipment like this as a matter of routine. He should not have had to intervene.

*Some day centre clients had to leave after they were 65 years...*

- One woman told us that her husband, who had had mental health problems and “heart problems”, had attended a day centre. However, her husband was asked to leave the day centre after he became 65 years of age. It seemed to our focus group member that the day centre had a policy about the age of the clients it would serve. It felt to her as if “pensioners are segregated.”

c) <i>How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.</i>
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*Quality of stimulation...*

*Some positive views...*

- People felt that some of the day centres made a real effort to keep clients stimulated and engaged in activities that were meaningful and enjoyable. In the words of some people:

- *“They [the clients] don’t just sit there... they have activities... it is all geared up to having a nice experience for people... they have a hairdresser on the premises”;*
- *“My mum meets people of her own age... she has started knitting again”;*
- *“They [the clients] interact with people... do boxes for orphans”;*
- *“There is a lot going on... go out to lunch.”*

*Some negative views...*

- However, a few people, felt that their relatives / loved ones were severely neglected in this regard. One woman described how her husband was taken into care, a nursing home, while she was in hospital with heart problems. She alleged that, during his stay in the nursing home, her husband, who had mental health problems and who was a wheelchair user, was routinely, *“just pushed into the TV room and left... might as well not have been there.”* She felt that, *“my husband would have been better with one-to-one care but there wasn’t enough staff”* She understood that it was against the law to have someone sitting for too long in a wheelchair. She alleged that her husband was *“kept sitting in the wheelchair the whole time he was at the day centre.”* She also felt that from the point of view of companionship, it was inappropriate for her husband to be in a place where the only other residents were twenty or thirty years his senior, *“he was 65 and he was in among eighty and ninety year olds.”* Fundamentally, she seemed to believe that her husband was placed there to be out of the way, *“...feeling that when he was in the TV room he couldn’t be seen.”* Another person who also felt that their loved one had not been adequately attended to described how his wife, who was then 50, had to share a TV room in a day centre with *“eighty to ninety year olds who sat and slept!”*
- Another person felt that the idea of involving clients in the every day running of the centre and thereby building up their self-esteem and confidence is given no more than lip service in some places. One person said that his/her daughter who attends the day centre, *“feels there is more she could be doing... they put her on the phones [i.e. appear to give her the responsibility of answering in-coming calls]... but then they don’t let her answer it!”* Allegedly a member of staff answers it. This practice is demoralising for the client.

*Nursing staff...*

- Some people described the nurses as *“terrific!”* Others said:

*“They do a terrific job... all the staff are lovely... my [relative] loves going there.”*

*“The staff do a really good job.”*

*“... very helpful.”*

*“My wife is under the care of one person”,* this was deemed as offering better personal attention.

*“staff are very helpful and if you have any problems you can talk to them...they are very approachable.”*

*Some important issues thought to be minimised...*

- One person felt that the care staff are *“very good mainly”* but that they *“can sometimes brush things under the carpet.”* They said that, *“one time a male*

*patient [fellow client at a day centre] grabbed my daughter by the breast... she [the daughter] did not want to go back... but they [the day centre staff] could not stop him [the offender] coming back to the centre.”*

**d) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc.***

*Difficult to gauge...*

- Some people found this difficult to answer since they felt so involved in their own situations they felt they had only limited experience of the situations of other people.

*Lesser service available if...*

- Client is not interested in computers or crafts – As one person put it, “*if you’re [client] not into computers and you’re not into crafts there is very little for you to do.*”
- Client has significant behavioural problems – It seemed that there was less service available for a person with behavioural problems. Suitable places seemed more difficult to find.

**e) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)***

- Those consulted made the following suggestions to improve the service at day centres:
  - Have more staff who can offer one-to-one care.
  - Have more reliable transport which is better organised and more flexible.
  - Look at how the transport could be organised to shorten the time each client spends travelling per day.
  - Have a backup transport option to cover when either something goes wrong (e.g. a bus breaks down) with the regular transport or the client needs transport from the day centre under special circumstances e.g. if sick.
  - Make sure that all drivers check that some one is at home before the client is dropped off. If no one is at home, have a clear and safe fallback procedure to safeguard the welfare of the client.

#### 8.1.2 SECOND PRIMARY CARE SERVICE – HOME HELPS

**f) *How would you rate the service in terms of ease of access?***

*Mixed experiences...*

- One man described how delighted he was with the access to the service. He and his wife were moving to Northern Ireland. While they were still in Wales, they had arranged the Home Help service to be put in place. They were amazed and delighted that *“the girls were at the door on the first evening as planned... the system worked like clockwork and we were very impressed... standards of these ladies are wonderful.”*
- Another person whose son has behavioural problems felt that access to a home help was very difficult in his/her situation. As he/she put it, *“home care workers can choose who they want to work with... only two home care people want to work with children... I have no back up service if anything goes wrong [i.e. a home help is off sick or on holiday] ...if she can't come in then nobody does.”*
- Others found the working hours of home helps made them functionally inaccessible. One person had a home help service to assist his/her daughter with personal care. Ideally such care was needed first thing in the morning. When he/she tried to explain this to social services he/she was allegedly told that the staff could not be asked to start work before 9am. However, at a practical level, if the care was given much later than this, the daughter *“would have missed her bus and we would have had to take her in [to the day centre]”*.

g) *How would you rate the service in terms of the overall quality of the service provided, and why?*

*Range of tasks undertaken deemed to be too limited...*

- Some felt that Home Helps were severely restricted in what they were allowed to do. For example, one person said, *“they [the home help] won't shower my mother”*. Many commented on the *“claims society”* in which they perceived we live, *“the whole thing [the very limited range of duties] is based on the fear of litigation... they [the Health Trust] have to protect the workers”*. Whilst the group fully supported the notion of protecting workers' rights, many felt that, in the case of this service, the restricted range of tasks now on offer was threatening to undermine the usefulness of the service overall.
- Some people in the group alleged that there were differences between what a home help would and would not do in different areas. One person claimed that *“some people [home helps] break the rules... they do such and such and tell you to keep quiet”*.

*Available hours deemed to be limited...*

- One person thought that the overall amount of service offered, in his/her case, two hours every fortnight, was too small. He/she felt that more respite was needed.

*h) How would you rate staff attitudes? i.e. How patient-friendly do you think professional staff are? e.g. medical staff, dentists, receptionists, counter staff in pharmacies – whichever applies in relation to that service etc.*

*Mainly good attitude but actions are restricted...*

- In the main, the attitude of the home helps was described as, “very good...more than helpful... more than good.”
- However, according to the group, many home helps are “hemmed in by regulations”, “afraid of the District Nurses... afraid of being reported and stepping out of line.” In short, it seemed that if the task being requested by the client / carer is not on the care plan, home helps are not allowed to do it.

*i) Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, males or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*More services for adults...*

- Those consulted felt that there were more home help services available for adults than for children.

*Carers themselves feel unsupported...*

- We were informed by one member of the group legislation pertaining to carers is to be passed through Parliament in the near future (2004). We understand that the intention of this is to look at the needs of carers themselves. However, some in the group believed that whatever legislation is passed, there will be very little, if any, funds allocated to putting something into action and that carers needs would continue to go unmet.

*j) In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the home help service:

- Provide more services for children.

## 2 SECONDARY CARE SERVICES (HOSPITALS)

k) *How would you rate the service in terms of ease of access?*

*Access...*

- One person felt that actually being admitted to hospital was a “very slow process... have to go to the GP... then have to go to the hospital... then get treated”. He/she felt that this was unacceptably long for someone in severe pain and said that one would be “nearly quicker going to A&E than the GP”.

l) *How would you rate the service in terms of the overall quality of the service provided, and why?*

m) *How would you rate the attitude of health service staff based in hospitals – e.g. Consultants, nurses, theatre staff, receptionists, porters etc? How patient-friendly do you think they are?*

The group considered these two topics together. Their comments were as follows:

*Some positive comments...*

- A number of people indicated that they were very satisfied with the overall quality of the care:
  - “staff were wonderful... I have no complaints about his [medical] care”;
  - Another person who accompanied his wife to hospital said that “she came away with a wonderful experience... felt someone was trying to help”. They were grateful for the “tremendous kindness [as they perceived] from the neurologist” and what they saw as generous allocations of time for consultations – 45 minutes with the neurologist and a half hour with the multiple sclerosis nurse. They also appreciated the Consultants checking the medication and their offer to come back and see them if they needed further help.
  - Another person described the quality of the service as “first class!” This person was impressed by the speed and ease of treatment. His/her mother, who had glaucoma, was referred to see a Consultant for laser treatment. “They looked at her within half an hour... kept her there... did the eye surgery and she went back later to have her eyes checked”.
  - One person commenting on the quality of service at the dentistry department considered it to be “helpful at all levels...very good”.

*However, there were also some negative comments...*

*Lack of proper beds...*

- There was a general discussion in the group about the lack of proper beds and how, allegedly, patients “*could lie on a trolley for three days*”.

*Perceived to be insufficient staff at the weekend...*

- A few people commented that there seemed to not be enough hospital staff on duty to cover the volume of patients attending at weekends. As one person put it, “*you [as a patient] don’t get as good a service at the weekend.*”

*Lack of sign language skills...*

- One female member of the group told us how the inability of hospital staff to speak in or understand sign language (makaton) caused serious distress for both her and her son. She explained, “*none of the staff were trained on communicating with [my] ...child.*” This woman sat with her son on the ward so they could communicate with each other. Allegedly, the ward sister did not allow her to eat anything on the ward so, “*after 18 hours*” of sitting at her son’s bedside without anything to eat she left her son to go to the canteen. She claims that she had only just sat down in the canteen when two members of hospital staff came and asked her to come quickly to the ward her son was on. Her first thought was her son had taken seriously ill. When she arrived the ward sister allegedly said to her, “*don’t you ever do that again!*” implying that she was not to leave her son’s side. The ward sister alleged claimed that the woman’s son had been “*kicking the staff... [and] we don’t have time for this!*” His mother claims that the ward sister told her that her son had to be asleep before she could leave to get something to eat. His mother also claimed that, “*they [the hospital staff] were holding his [her son’s] foot down.*” It was then clear to her what had happened. She explained that raising his foot in the way he had done was his way (in makaton) of trying to “*let them know he was needing a poo.*” The mother felt that the misunderstanding, which had caused her and her son great distress, was entirely avoidable if someone on the ward had been able to communicate in her son’s language.

*Problems with transport if no access to car...*

- One member of the group felt that, “*if you don’t have transport of your own it can be extremely difficult... you would be waiting a very long time to get an ambulance... [and] if you are not well, that could be a problem.*”

n) *Do you think that there are any circumstances where people receive a less or more favourable service than others? e.g. because they are old or young etc, male or female etc, affluent or disadvantaged, disabled or non-disabled etc.*

*Better service...*

- One person suggested that one got a better quality of service (e.g. faster, better treatment) as a private patient. However, another person claimed that the NHS pick up the cost of errors in the private sector, *“if anything goes wrong in a private hospital they will take you in an ambulance to a NHS hospital... they want to put you out as quickly as possible so they can get the next person in.”*

*Lesser service...*

- One person considered that a confused or vulnerable person was at risk of receiving lesser service. This person alleged that when he/she was in hospital, *“I refused a tablet because it wasn’t right.”* He/she claimed that the nurse had asked him/her to take *“two and a half tablets”* when he/she was only accustomed to taking *“two and a half mls”* (a much smaller amount in the context). As he/she explained, *“I made them [the nurse] go over it again.”* He/she was very concerned about this error since the tablet was allegedly for *“slowing down the heart”*. The question was posed, *“what would have happened if I had been a confused person?”*.
- As indicated above, one person felt that without access to one’s own transport one could be waiting a long time for an ambulance.
- Again, as indicated above, one member of the group pointed out that a patient could receive a lesser service if the staff were unable to communicate in his/her language (in this case makaton).

o) *In your opinion, what is the single most important thing that should be done to improve the service? (NOTE: This list is not prioritised)*

Those consulted made the following suggestions to improve the service at hospitals:

- Employ more Consultants to reduce waiting times.
- Ensure that there is ready access to someone who can communicate in sign language, especially on a children’s ward.
- More beds, not trolleys.
- Better attention and care for elderly people during meal times – As one person said, *“they [hospital staff] just set the dinner on [a] tray at the end of the bed... the person maybe can’t reach it or see it... if it is not eaten they take it away... they don’t query why they [the patient] didn’t eat their dinner.”*

- Improve hygiene on wards and in the hospital in general. As one person put it, *“they should bring back the matron... and get rid of the managers... they wouldn’t have the problem with cleanliness and MMRI... she would do the spot checks... everyone would be kept on their toes.”* Another person perceived that the private sector cleaning services were of a very poor standard and needed closer supervision. There was a general feeling that the staff carrying out the cleaning in hospitals were underpaid and, consequently, had no real interest in doing a good job. One person called for *“better management of cleaning service... [because staff are] paid buttons.”*

### 9.3 PUBLIC HEALTH

p) *As a result of health promotion messages you may have seen in the media or information leaflets, have you changed your lifestyle in any way? If so, what was this? Was it a temporary change or a permanent one? What aspect of the message convinced you to change?*

*Health promotion adverts thought to have little effect...*

- One person commented on the negativity of many of the health promotion messages. To him/her they seemed somewhat patronising, *“like parent and child”*, and in the long term, as he/she saw it, did not eradicate the problem. In his/her words, *“I feel there can be a very negative message... AIDS... we were bombarded and then it [the series of adverts] disappeared but AIDS is still here.”*
- It also seemed that the topics chosen were more a series of disjointed issues rather than being an integrated sustained approach to educating the public. As one person put it, *“when they have done one thing [topic] they move on to something else... smoking... obesity....”* It was felt that health promotion in general needed to find *“a different way of getting the message across instead of bombarding us... makes you switch off.”*
- Whilst another person felt that the binge drinking adverts on TV were *“very good... improved your general awareness... general knowledge”*, they were not convinced that the message was reaching the target audience or that it was going to solve the problem. He/she felt that legislation and enforcement had more of a part to play. As he/she put it, *“is it going to solve the problem of binge drinking?...law [as regards underage drinking] needs to be tightened up... not sure if [these adverts] reach [and have an effect on] young people... it has created awareness but maybe not to the right people.”*

#### 9.4 GENERAL ISSUES

q) *What do you feel is the most important problem facing health and social services in Northern Ireland today and why? And can you make one suggestion as to how this problem should be tackled or resolved?*

- The “baby boomers” are getting older and living longer.
- It was thought that research into DNA and the links between DNA segments and health / illness would become an even more significant industry in the future and that money for the health service would be diverted into research.
- Lack of staff in hospitals.
- General lifestyles of the Northern Ireland population with people consuming high levels of fats and convenience foods and not taking enough exercise thus storing up health problems.
- Obesity.
- Alcohol and drug misuse.

r) *Excluding prescription charges, have you paid for any health or social care related service directly from your own money in the last 12 months (i.e. and not include through a private medical insurance scheme)? Why did you choose to pay for this health or social care service?*

*Adaptations...*

- Some carers told us that they had used their own money (circa £1k to £2k) having a lift installed in their respective homes. They said that the assessment processes takes so long, “*it was going to a year or more*”, that the people who need the lifts and their carers could not afford to have their quality of life compromised for that long. Some therefore pay for the adaptation out of their own money. However, it was also pointed out that even if the assessment demonstrated that the person being cared for would be eligible for a lift, the money cannot be paid retrospectively.
- Another carer told us that, in order to better care for a relative, he/she had used his/her own money to have a more suitable showering facility installed in his//her own home.

s) *How effective do you think Health and Social Services is in resolving complaints?*

*Not good at addressing complaints...*

- Two people, who were both unhappy about the quality of service provision, told us about situations where, rather than go through a formal complaints procedure, they took the matter to a higher authority and both appeared to have got satisfaction very quickly.

- One carer explained how he/she had a son who had an obsessive-compulsive disorder. He/she claimed that he had been waiting for treatment for three years. His health had deteriorated to the point where he was allegedly “*threatening to commit suicide every other night.*” This person wrote to the Health Minister, outlined the situation and asked for help. Apparently, “*two weeks later... he got treatment.*”
- Another person described how when his/her daughter was not being offered the health care that she urgently needed and after trying to be reasonable, he/she finally “*threatened [them]... with Esther Ransten... suddenly everything was possible!*”
- There was a general sense in the group that:
  - One had to be very assertive to get what was needed;
  - Sometimes little was achieved by being reasonable and waiting; and,
  - Key influencers have to be brought in, or threatened to be brought in, before anyone takes the matter seriously.