

***Public Attitudes to Health and Personal Social Services
in Northern Ireland 2004***

Appendix 5

Detailed Findings from Each Focus Group

November 2004

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 - **Steer;**
 - **South Armagh Women’s Family Health Initiative;**
 - **Cedar Foundation;**
 - **Northern Health Action Zone;**
 - **Western Health Action Zone;**
 - **Senior Citizen’s Consortium Sperrin & Lakeland;**
 - **Banbridge Carers Group;**
 - **Coalition on Sexual Orientation;**
 - **Engage With Age;**
 - **Newry and Mourne HSS Trust;**
 - **Royal National Institute for the Deaf;**
 - **Ballynafeigh Community Development;**
 - **Northern Health and Social Services Board Ethnic Minority Steering Group.**
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We would stress that the opinions expressed in this Report are strictly those of the persons who gave them, not RES.

CONTENTS

1	INTRODUCTION AND BACKGROUND	167
2	SUMMARY OF METHODOLOGY	167
2.1	IDENTIFYING CLIENT GROUPS	167
2.2	HOSTING THE FOCUS GROUPS	169
2.3	CHOOSING THE SAMPLE	169
2.4	USE OF INCENTIVES	169
3	MENTAL HEALTH SERVICE USERS AND CARERS	170
4	RURAL FAMILIES	185
5	PEOPLE IN A DISADVANTAGED NEIGHBOURHOOD	197
6	PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES	209
7	TRAVELLERS	221
8	OLDER PEOPLE IN RURAL AREAS	229
9	CARERS	242
10	PEOPLE OF DIFFERENT SEXUAL ORIENTATION	258
11	OLDER PEOPLE IN URBAN AREAS	271
12	PEOPLE WITH A LEARNING DISABILITY	286
13	PEOPLE WITH HEARING IMPAIRMENTS	294
14	YOUNG PEOPLE	311
15	PEOPLE FROM ETHNIC MINORITIES	322
16	GENERAL FINDINGS	337

1 INTRODUCTION AND BACKGROUND

The Department of Health, Social Services and Public Safety (DHSS&PS) appointed Research and Evaluation Services (RES) in March 2004 to assist it with a public consultation exercise.

The public consultation exercise was carried out in two parts:

- a series of 13 focus groups, (this Appendix relates only to the findings of the focus groups); and,
- a telephone survey of Northern Ireland adults (details of this are available in the main Report and Appendices 1 and 2).

2 SUMMARY OF METHODOLOGY FOR FOCUS GROUPS

2.1 IDENTIFYING CLIENT GROUPS

The Department worked with the four Regional Strategy Area Sub-Groups (established as part of the Regional Strategy) to identify 'hard to reach' client groups i.e. those groups whose voice would not necessarily be heard via a telephone survey. The Health and Social Services Councils were also closely involved in the planning and selection of these groups.

The Department liaised with the Regional Strategy Area Sub-Groups and the Health and Social Services Councils to identify locally based groups in each area to represent the views of the client groups chosen.

The focus groups took place during April and May 2004. Full details of the focus groups hosted are shown in Table 1 overleaf.

Table 1: Details of Focus Groups Hosted					
Group No	Profile	Contact Organisation	Date	Venue	Attendees
1	Mental Health Service Users and Carers	Steer	1 Apr 04	Steer, The Diamond, Londonderry	11
2	Rural Area (families)	South Armagh Women's Family Health Initiative	7 Apr 04	Mullaghbawn Community Centre, Mullaghbawn	10
3	Physical (sensory disability)	Cedar Foundation	14 Apr 04	Balmoral Training and Resource Centre, Belfast	6
4	Neighbourhood (disadvantaged)	Northern Health Action Zone	14 Apr 04	Gortalowry House, Cookstown	9
5	Travellers	Western Health Action Zone	15 Apr 04	Community House, Omagh	9
6	Older People (rural)	Senior Citizen's Consortium Sperrin & Lakeland	20 Apr 04	Gortmore House, Maguiresbridge, Co Fermanagh	8
7	Carers	Banbridge Carers Group	21 Apr 04	Banbridge Enterprise Centre, Scarva Road	9
8	People of Different Sexual Orientation	Coalition on Sexual Orientation	24 Apr 04	Clanmil Housing Association, Northern Whig Building, Belfast	6
9	Older People (city)	Engage With Age	26 Apr 04	Grosvenor House, Glengall Street, Belfast	11
10	Learning Disability (service users)	Newry and Mourne HSS Trust	28 Apr 04	Laurels Day Centre, Drumalane Road, Newry	8
11	People with Hearing Impairments	Royal National Institute for the Deaf	5 May 04	RNID, Wilton House, College Square North, Belfast	9
12	Young People (13-16 years)	Ballynafeigh Community Development	18 May 04	Ballynafeigh Community Centre, Ormeau Road, Belfast	10
13	Ethnic Minority	Northern HSS Board Ethnic Minority Steering Group	20 May 04	Ballymena Inter-Ethnic Forum, Ballymena	6
TOTAL Attendees					112

2.2 HOSTING THE FOCUS GROUPS

The Department worked in liaison with the locally based groups to agree a mutually convenient date, time and venue for each of the focus groups. In parallel to this the Department and RES jointly agreed a draft agenda for the focus groups. Written parental consent was obtained for all of the under 16 year olds who attended the young persons focus group.

RES hosted and tape-recorded each of the focus group sessions. We also asked participants to complete a monitoring form. The statistics from this are shown at the beginning of each chapter.

Given that it was not feasible to have asked focus group participants about all of the primary care services, it was agreed with the Department that each group of participants would be allowed to choose which primary care services they had most experience of or wished to comment on. Hence, in the Report that follows, we explain the number of focus groups where participants opted to comment on each of the specific services. Inevitably, there were some primary care services that none of the groups (participants) chose to comment on.

Apart from these specific set of questions, all groups commented on all other questions.

2.3 CHOOSING THE SAMPLE

The participants for each focus group were chosen by each locally based organisation.

2.4 USE OF INCENTIVES

With the Department's consent, RES gave each adult participant £20 in cash to cover any out-of-pocket expenses and their time for attending. In the case of the young people's focus group, a £10 donation was made for each young person who attended (this reflected the fact that the young person's focus group lasted only one hour compared with the adult groups which typically lasted two hours).

3. MENTAL HEALTH SERVICE USERS AND CARERS

FOCUS GROUP:	MENTAL HEALTH SERVICE USERS AND CARERS
VENUE:	STEER, 15 THE DIAMOND LONDONDERRY
DATE	1 st APRIL 2004
NUMBER OF PARTICIPANTS:	11

Profile of Participants			
		Number	%
Sex	Male	7	70
	Female	3	30
Age	Under 18	-	-
	18-24	-	-
	25-44	6	60
	45-64	4	40
	65-74	-	-
	75+	-	-
	No Answer	-	-
Disability	Yes	9	10
	No	1	1
	No Answer	-	-
Dependent Children	Yes	3	30
	No	7	70
	No Answer	-	-
Other Caring Responsibilities	Yes	-	-
	No	10	100%
	No Answer	-	-

3.1 PRIMARY CARE SERVICES

The group chose to discuss:

- *Community Psychiatric Services; and,*
- *GPs.*

The feedback was as follows.

3.1.1 FIRST PRIMARY CARE SERVICE: COMMUNITY PSYCHIATRIC SERVICES

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

Generally, very poor access. Far too long to wait to get an appointment...

- The general view was that people had to wait for approximately six months to get an appointment with community psychiatric services. The group felt that this was far too long.
- One person indicated that he/she was told that there were not enough Community Psychiatric Nurses (CPN) and that as a result he/she assigned a social worker instead. At that time they were in the process of getting their medication changed. They felt that being assigned a social worker was a very unsatisfactory arrangement since they considered that a social worker was not qualified to offer them the support they needed, for example, *“what does a Social Worker know about medication?...you need extra support [properly qualified staff] during a change of medication.”*
- One person who had been assessed as being at risk of committing suicide had an emergency appointment requested by his/her GP. Eighteen months on, this person was still waiting for an appointment.
- There was a widespread feeling in the group that access to CPNs was *“rationed.”* Ten to fifteen minute sessions were considered inadequate given the complexities of the illnesses with which many patients were dealing.
- One person summed it up as a *“broad picture of neglect... [people with mental health conditions] not seen as first class citizens... it is lottery system”* [whether or not a person gets allocated a CPN]. Those consulted considered that being allocated a CPN had more to do with luck than a proper assessment of need. There was a general feeling of powerlessness to influence whether or not an individual would be successful in being allocated a CPN. Professionals were perceived as holding the power to make these choices. As they saw it, *“...they [the medical professionals] roll the dice, if you get a double six ... you get a CPN, if it comes up six you get nothing.”*

- Another person, who had felt suicidal most of his/her life, described how, for someone with a mental health condition, lack of proper support can increase their feelings of isolation and vulnerability, *“there was a time in my life when I didn’t look for help, but now that I want help it is not available... I feel pushed away by community psychiatric services.”*

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

Lack of general information...

- One person who was new to mental health services felt let down that *“nobody explained mental health services”* for example, what was available, different therapeutic options etc. *“They [mental health professionals] don’t give you enough information.”* This was important because people were *“terrified of the old image”* of mental health services and psychiatric hospitals which were seen as confining, regimented and offering poor service. This image seems to have some foundation in reality (see below).

Quality of service in Psychiatric Hospitals perceived as very poor...

- One person said that even having been assigned a named nurse in the psychiatric hospital was of no benefit. The named nurse took no interest in them. *“They [the named nurse] didn’t make me feel comfortable [at ease in my surroundings]... I was just not known to him... [I was] an unknown face.”*
- Another person described his/her experience of being an in-patient in a psychiatric hospital (Gransha) by saying, *“my experience was of being held down and over drugged... no-one got in touch with my GP... took about eighteen months to see a psychiatrist... should have been under the care of a CPN but I didn’t get one.”*
- Another person indicated that in relation to his/her therapy in psychiatric hospital, *“I was only offered ECT (Electro-Convulsive Therapy).”* They described ECT as *“barbaric in the 21st century.”*
- One person in the group described what he/she regarded as over use of drugs in the care of a person with a mental health condition, *“I have visited people in psychiatric hospitals... zombies for patients... I was troubled when I came out again.”*
- Another person commented that in his/her opinion there was *“little or no support for people coming out of [psychiatric] hospital”*. He/she felt that this was a key stage and that a care package, which is appropriate to the needs of the person, needed to be put in place to ease the transition.
- One of the people who had experience of being a patient in a psychiatric hospital described the surroundings as *“dilapidated and dismal... [the physical appearance] looks very negative.”* He/she felt that the poor physical condition of the premises actually added to the sense of depression.

- Another person indicated that the location of many psychiatric hospitals i.e. in out of town locations, only served to further stigmatise people with mental health conditions. It seemed to reinforce the stereotypical view that people with mental health conditions were on the outside of the community, that mental health conditions were something to be ashamed of and needed to be hidden away. For example, the local psychiatric hospital was “...three or four miles from the city centre... there is a lousy bus service [to it] ...it takes £4 in a taxi to get to it... it [the out of town location] isolates people and maintains the stigma by keeping people outside the community.” It was suggested that a number of smaller psychiatric units (say 8 bed units) needed to be provided within the community.

People with mental health conditions being assigned tasks well below their level of competence in occupational therapy...

- One person described how he/she was offered occupational therapy but did not feel that this was appropriate. Indeed, given his/her skills and competencies, he/she described having found the experience humiliating and degrading. Increasingly, it became a major stress in itself to attend. During this experience he/she had “seen a CPN for 20 minutes” and during that time “...the only thing the CPN focused on [was] why I was not attending ITO [Industrial Therapy Organisation].”

Rushed appointments with psychiatric services...

- Several indicated that they found the attitude of psychiatrists, “very patronising... [in addition] ...you only get 10 minutes.” For many, this was simply not enough to be effective at any level, “I feel the same when I go out as when I go in... I don't really get anything from it.”

Over-reliance on medication alone. Need for more Cognitive Behavioural Therapy...

- The group generally considered that, from GPs to Psychiatrists, there was an over-reliance on medication alone to address their patients' mental health conditions. As one person put it... “the tablets deal with the symptoms but they don't address the real causes, the tablets mainly maintain your health... [but they] create a dependency.” As another person put it, “all I was ever offered was medication, medication and ECT ...too much reliance on medication... there is a need for it... but there is overuse of it... they [medical professionals] are too quick to over prescribe it... there is more than medication to help people recover.”
- There was a general view amongst the members of the group that they did not want to be dependent on drugs for life. Some were cynical about the motives of the drug companies and the way in which they seek to influence the prescribing habits of doctors, “...they [drug companies] need us to take their products... there is no profit [for them] in our recovery”.
- The group generally considered that there were more effective ways of helping people recover. There was considerable discussion about cognitive behavioural therapy (CBT) and the long lasting benefits of this approach. There was a general

view that CBT should be offered more frequently, either alone or in combination with medication.

- There was general criticism at the small number of CPNs who have had training in CBT this coupled with the shortage of CPNs generally, meant that very few mental health service users could potentially benefit. One person expressed the view that, “*CBT is the most effective treatment for people with depressive conditions and schizophrenia... [however], only a tiny fraction, 1 in 10 service users have cognitive behaviour input.*” In other words, the most effective therapy was the least available. To this particular individual this did not appear to make sense. Another person, who had experienced the shortage in CBT first hand, criticised what he/she saw as a serious, “*...lack of opportunity to see the specialists... still waiting for cognitive therapy [for] four years now.*”
- Another person described having been recommended to receive cognitive behavioural therapy and had been allocated a CPN. However, when this particular individual met with the CPN, he/she “*had no notes... knew nothing about me... I thought this was strange... stupid.*” The participant also described feeling angry and let down that a valuable opportunity which could have helped him/her, for which he/she had waited a considerable length of time, had been squandered through a complete disregard for what he/she saw as fundamental.
- Many people described how unsupported they felt by community psychiatric services. One person in the group described having “*...seen a Consultant three times in four years*”. He/she felt that in given the seriousness of the situation this was definitely “*not enough.*”

Perceived lack of support for GP by Community Psychiatric Services...

- It seemed to many people in the group that, the “*GP does all the work*”, writes letters etc, with very little support in reply from community psychiatric services.
- Several people gave examples of situations where their GP had requested information from community psychiatric services and no reply or even acknowledgement of receipt of the request had been given. It seemed to those consulted that community psychiatric services did not regard making replies to GPs as important.

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.*

Some positive attitudes on the part of GPs...

- One person, who had several experiences of feeling suicidal, described how they had had a “*bad experience*” with a CPN. The CPN did not appear to understand or be able to support their needs. The person expressed gratitude that their “*GP now looks after me*”. He/she was especially grateful that, between visits, the GP took the trouble to get “*...people [from the surgery] to phone to make sure*

everything was alright [with me]... really helpful.” He/she was grateful too that the GP gave them extra time for their appointments, “it wasn’t just a 8 minute consultation”.

- Another person who had a bad experience with a CPN described how his/her GP, *“took the situation in hand... explained a routine for me to follow... gave me a structure to my day.”* This person found this intervention extremely supportive.

Some positive attitudes on the part of CPNs...

- One person described how helpful it had been that his/her CPN had begun their working relationship by saying that they [health professionals] were *“recruiting me as a partner in my own health care.”* This particular individual especially valued this since in his/her experience of other CPNs and professionals within the mental health sector, *“...a lot of them demean you and disregard your intelligence... this person never patronised me.”* However, underlining what was perceived as a chronic and grave shortage of appropriate professional support, he/she said, *“...it took me four years of using this [mental health services] before I found someone who treated me like a human being... there has to be a change of attitude.”*

Patronising attitude of some GPs, Psychiatrists and CPNs...

- Several people in the group were unhappy with the attitude of their GP or Psychiatrist towards them. One person commenting specifically on his/her own experience said, *“they [GP or Psychiatrist] don’t believe the side effects”* that he/she [the patient] described to them. This person expressed frustration at their patronising attitudes.
- Another person alleged that he/she had experienced resentment from a Consultant Psychiatrist when he/she was able to use hospital jargon. He/she said, *“they [the Consultant] really resented my knowing their language... I enquired about my medication... my diagnosis and prognosis...they said, ‘you don’t need to know that!’”*
- Another person commented on the insensitivity of one CPN he/she had encountered. This person explained that at one point he/she had *“felt like my world was ending.”* At this time, this particular individual was having difficulty adhering to the therapy that he/she had been given. He/she was allegedly told by the CPN, *“You never stick to anything!”*. The person concerned said that what he/she needed at that time was more encouragement. Instead, *“they [the CPN] left me in tears... I felt like a failure”*.

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.*

Services for young people living west of the Bann perceived to be very poor...

- One person commented on what he/she perceived as being very poor services for children / young people with mental health conditions. As he/she explained, “...children are put into adult psychiatric units without access to adequate specialists... there are no residential psychiatric children’s services west of the Bann.” Furthermore, he/she added that, “...the WHSSB [Western Health and Social Services Board] has access to two psychiatric beds for children in Bangor!... how will the parents be able to maintain the relationship with their children over this distance?”

People with private medical insurance get faster access...

- Some commented that people with private health insurance had “no time to wait” when it came to accessing all types of medical services.

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 within community psychiatric services for people with mental health conditions:

- Change of attitude – In general, the group felt that there needed to be a change of attitude amongst mental health service planners and Psychiatrists in particular. As one person put it, “...treat people with a psychiatric illness as human beings... , there is a terrible lack of care... there are some staff... who don’t seem to care, the care element is gone... some are very good but some are burnt out.”
- Involve service users – The group recommended that community psychiatric services involve present and past service users more fully in how mental health services are designed, how the quality of service is defined and how this is monitored. Others wished to see past and present service users being involved in the design and delivery of training for professionals working in this field. Referring to the patronising and unhelpful attitudes which many mental health services users appear to have experienced, one person stated that being involved in staff training would “ensure a real and substantial change in [staff] attitude” towards people with mental health conditions. As another person put it, “service users are experts because of their experience... we are a fantastic resource... use us! There is no text book that will ever teach you... if you don’t experience [a mental health condition]... you won’t know what it is like. We are here for you [service providers / policy makers] ...experience is a great thing... you can put people at their ease... explain there is hope.”
- Work to change public attitudes to mental health – one person reflecting the general view of the group said that he/she would wish to see health and social services changing, “Joe public’s attitude... want people to accept me for who I am, warts and all... want to be accepted and feel part of the community... instead of being stigmatised.” Another person commented that when he/she had been in general hospital with a heart condition, he/she had received lots of visitors. However, whenever he/she was admitted to a psychiatric hospital only his/her

partner and children visited. He/she perceived this as a reflection of the stigma that is associated with mental health conditions in society today.

- Upgrade the physical condition of the psychiatric hospitals.
- Provide more opportunities for counselling and talking.
- Reduce reliance on drug-only therapeutic regimes and provide greater access to counselling therapies and cognitive behavioural therapy especially.

3.1.2 SECOND PRIMARY CARE SERVICE – GPS

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

In general, people did not find it difficult to get an appointment with their GP.

Problems for some in getting registered...

- However, one person in the group indicated that he/she had had difficulty getting registered with a GP. He/she described having tried to register himself/herself together with his/her parents (both of whom had mental health conditions) with two different doctors and had been informed that they were “full.” Then they contacted the Central Services Agency (CSA) he/was she signed-up with a GP whose list had previously been full. This particular individual described the experience with GP practices as being “treated with utter contempt.” He/she was convinced that they were refused on the grounds that they had mental health conditions and would be regarded as difficult. Given the assistance received from CSA, he/she felt that, “CSA needs to be advertised heavily... not just stuck in Belfast... they need an office in Derry.”

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 above two topics were considered together.

There were mixed views on the quality of the service provided. This was often dependent on the individual GP.

Some positive experiences of GPs...

- A few people in the group indicated that they had a “good relationship” with their GP. As one person explained, “he takes his time to explain things... he also recommended me to STEER.”

Some negative experience of GPs...

- Another person in the group who reported visiting a GP for support for depression was allegedly told that he/she would “*grow out of it!*” This person changed GPs and indicated that the new GP was “*very understanding.*” This person appreciated the fact that he/she could “*... get an appointment at any time... even for a chat.*”
- Another person alleged that he/she had met with an aggressive and patronising attitude when requesting counselling services. Allegedly he/she was asked, “*what do you need it for?*”

Need for GPs to improve their knowledge of relevant mental health issues and support services...

- One person in the group felt strongly that “*GPs should be looking into CBT rather than [exclusively] medication.*”
- One member of the group felt that, in general, “*GPs are not aware of the community / voluntary services out there.*”
- One individual also commented that in he/she opinion, “[GPs] *don’t have a real understanding of mental health issues... [according to an article they had read in the recent past] ...7 out of 10 GPs do not receive adequate training in mental health [issues]... it is a lottery who you get.*”

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.

- The person who had difficulty registering with a GP (and registering parents) felt that this would have been very straightforward had they not had a history of mental health conditions.

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 GPs to people with mental health conditions:

- Prompt appointments – in general, the group felt strongly that in their situation, appointments with GPs should be available at very short notice, “*when you ring up you want an appointment straightaway... you need an appointment the same day.*” As one person put it, “*if I feel suicidal... [with] severe depression... a week is too long!*” Some asked that if a face-to-face appointment was not possible, could a GP phone them and at least speak to them?

- Need 24-hour service for psychiatric services – one person pointed out that there should be access to an emergency psychiatric service available. He/she contended that appointments that were available only during normal working hours were not enough. In he/she words, “*mental health does not start at 10 and end at 4...it [a service which covers 10 to 4] is no good if you are feeling suicidal at 4 o’clock in the morning... [there needs to be] a crisis team to operate 24/7.*”
- Each practice should have a specialist in mental health issues – one person pointed out that many modern health centres have a range of specialists e.g. dieticians, chiropodists etc. He/she suggested that there should be specialists in mental health services as well.
- More time for talking and less reliance on medication – there was a general view that doctors should, “*give you more time instead of reaching for medication all the time.*” As one person said, “*if you are feeling suicidal and they give you a tablet... you need more than that.*”
- Change public attitudes – Many of those consulted felt that the general public has a very negative view of mental health conditions and consequently, many people with mental health conditions feel stigmatised. The group felt that the Department should strive to change this attitude, “*mental illness seems to be a taboo subject.*”

3.2 SECONDARY CARE SERVICES (HOSPITALS)

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

Routine access perceived to be good...

- Access to hospital services was regarded as generally good.
- One person commented that the waiting times at hospital clinics had improved. Waiting for 20 – 30 minutes for an appointment at such clinics was regarded as acceptable.

Too long to wait to be seen by a specialist...

- However, others added that they had found it difficult to get appointment with a specialist, “*waiting lists are long... [I was] waiting at least six months to get gallstones seen to.*” Most felt that six months was generally too long.

Insufficient car parking...

- Car parking – We were given to understand that at the local hospital, “*... car parking is a problem... car park full of staff [cars]... would need a multi-storey.*” The group consulted indicated that even charging a small fee for parking to help affray costs would be acceptable.

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?*

Again, the above two issues were considered together.

General Accident and Emergency services were regarded as good, except for provision of mental health services...

- Those who commented on the general standard of service at the local Accident and Emergency Unit described it as “*second to none.*” In their opinion, the “*nurses are understanding and caring... cardiologist... excellent.*” There was a general view that people were “*very happy with the experience [of accident and emergency] ...people were very caring and very professional.*”
- In contrast, others commented on what they perceived as a bad attitude by some A&E staff in relation to mental health issues. In their opinion, staff demonstrated a very poor understanding of mental health conditions. One person alleged that, “*if you present with self harm or... suicide attempt... you can get a negative attitude from the staff... as if you are [needlessly] taking up a hospital bed... I think they think you are wasting their time.*” They also commented on what they regarded as entirely inappropriate accommodation for people with mental health conditions presenting at A&E. As one person explained, “[you] *normally end up on Ward 2... full of all sorts... you are very vulnerable... this is the last place you want to be! ...drunks... [some of those who are intoxicated] ...can be very aggressive.*” In short, they considered that people who were intoxicated or who were aggressive should be separated from those who are not. It was felt that “*there is a need for a specialist self-harm department.*”

Positive attitude of nurses but bad attitude by some hospital Consultants...

- One person described how they had taken an overdose and were waiting on a liver transplant. He/she praised the supportive attitude of the nurses, “*they were fantastic.*” However, it was alleged that the hospital Consultant who was attending this particular individual said to him/her before a liver transplant had been identified, “*don’t worry you still might die.*”

Perception that system in general is overloaded...

- Some people commented that Altnagelvin Hospital “*feels understaffed generally... staff are burdened by the hours... amount of people on trolleys... scary... [especially at the time of the chest epidemic] ...some waiting for hours to be seen... not the staffs’ fault.*”

Poor hospital hygiene...

- One person said that in he/she opinion, *“the cleanliness of Altnagelvin has gone down hill drastically.”*

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.*

- Private patients - There was a general perception that if a patient paid to have a service privately that it was of a higher standard than the NHS. Also, the service was provided faster as, *“money talks!”*
- Assertive people - There was a general feeling that those who were assertive and could discuss issues confidently with medical professionals would get a better service. As one person put it, *“[you are likely to get a better service] ...if you can stand up for yourself... you have to see about yourself.”*

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

Those consulted made the following suggestions to improve the service at hospitals for people with mental health conditions:

- Eliminate the prejudice about mental health conditions based on ignorance – There was a general feeling in the group that many health professionals do not fully grasp what it is like to experience a loss of good mental health. Consequently, this affected their attitudes and behaviour towards people with mental health conditions. As one person explained, *“they need to realise that feeling suicidal is an illness”* i.e. and not a weakness of character.
- Have more staff at A&E.
- Have a specialist unit at A&E for self-harmers.
- Staff within hospitals should take time to explain matters in more detail to patients.
- Improve general hospital hygiene.

3.3 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 reactions to TV adverts...

- One person said that they stopped smoking after they had “*seen that advert about going into your lungs... I realised that that was why I was coughing.*” However, a non-smoker in the group thought it was overly graphic, “*I find it very offensive.*” Some others thought the advert was “*educational.*”
- Some thought that the recent TV adverts about binge drinking were “*very good.*”
- The “*never, ever drink and drive*” adverts on TV were also thought to be beneficial.
- One person commented that the TV adverts on wearing a seat belt were so graphic that it made him/her wear a seatbelt while driving.
- One person pointed out that the “*Heads Away – Just Say*” campaign was a good example of how partnership between the Health Promotion Agency and service users could work. The group indicated that it would welcome more collaboration of this type.

3.4 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?*

Those consulted identified several key issues:

- Ageing population – one person commented, “*we [in Northern Ireland] are going to have a lot of older people.*” They were concerned about how GPs and hospitals would cope or not cope if there was another flu epidemic. He/she feared, “*there will be no place for them to come to.*”
- Arthritis – one person thought that there was a rising trend in the incidence of arthritis.
- Drug misuse – there was a concern that the general level of drug misuse was rising.

- Lack of funds for capital projects – some expressed concern that there did not seem to be enough funding available in general for hospitals.
- Stigma that goes with mental health conditions – as one person put it, “*I don’t want to be stigmatised for [having poor] mental health.*” There was a general feeling that the Department should do more to educate medical staff and members of the public about mental health conditions.
- Medical model – there was a general view that, as one person put it, “*the biggest problem is the medical model of mental health. It does not adequately or appropriately meet the ends of people with mental health [conditions]. If this was changed, it could open up the gateway to more community based services.*” Reflecting on his/her personal experience he/she contended that, “*the process of being in [psychiatric] hospital is anti-therapeutic... the environments are hostile, intimidating and unpleasant... [future service provision] needs to be based on community based psychiatric units [on a small scale] ...for example, eight beds*”.
- Collective action by service users - one member of the group felt that a key issue should be encouraging service users to act collectively to lobby for and directly improve service standards. He/she said that attitudes to mental health “*have started to improve since we [as members of STEER] have started to speak up... now starting to open doors... [service providers] starting to listen to us... long way to go.*” It was felt that individual efforts were less likely to be effective, “[you need to] *have a voice from a group... on your own you can’t do anything... can’t bring about change.*”
- Current reviews – There was some optimism in the group that the current mental health and disability reviews would bring about a measure of improvement, “*looks very positive.*”

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?*

Operation...

- One person described how he/she had become aware of a condition that he/she had which needed an operation. In his/her opinion, the waiting list was too long and the anxiety of knowing that they needed the operation to address the condition was “*stressing me [him/her] out.*” As a result, he/she paid to have the operation privately.

Alternative therapies

- One person in the group had used his/her own money to purchase alternative therapies. He/she had found these treatments to be helpful for the condition and also reported experiencing fewer side effects.

Counselling services...

- Two people indicated that they had tried to access counselling services through the NHS. Both felt that the waiting to get counselling was too long and they went privately.

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

Mental health service users too frightened / disempowered to complain...

- We were given to understand by the group that STEER provides an advocacy service, “...we prefer to resolve a situation before going through the complaints procedure.”
- However, one person, who is involved with the advocacy service alleged that he/she knew “about forty people who have legitimate cause for complaint but won’t because they fear retaliation... they fear they would be denied access to the service... feel too threatened... too disempowered.” He/she considered that what is needed is a “proactive, well-funded mental health commission... with a proper ratio of service users [and ex-service users] on it... [that way] when cases of abuse / neglect come up, they would be addressed.” The current Mental Health Commission was perceived as “...ineffective... won’t advertise services... fear they would be inundated.”

4. RURAL FAMILIES

FOCUS GROUP:	RURAL FAMILIES
VENUE:	MULLAGHBAWN COMMUNITY CENTRE, MULLAGHBAWN
DATE	7 th APRIL 2004
NUMBER OF PARTICIPANTS:	10

Profile of Participants			
		Number	%
Sex	Male	-	-
	Female	10	100
Age	Under 18	-	-
	18-24	-	-
	25-44	4	40
	45-64	5	50
	65-74	1	10
	75+	-	-
	No Answer	-	-
Disability	Yes	3	30
	No	7	70
	No Answer	-	-
Dependent Children	Yes	7	70
	No	3	30
	No Answer	-	-
Other Caring Responsibilities	Yes	4	40
	No	6	60
	No Answer	-	-

4.1 PRIMARY CARE SERVICES

The group chose to discuss:

- GPs; and,
- Allied Professions to Health.

The feedback was as follows.

4.1.1 FIRST PRIMARY CARE SERVICE – GPS

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

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

These topics were considered together.

Lack of access...

- The level of access was generally considered to be poor, “*during the week it would probably be fair but at the weekends it is a disgrace*”, “*you don’t have a service at the weekends*,” “*...no Saturday surgery*”, “*no facilities for workers [i.e. no evening surgery]*.” One person summed it up, “*you need to be sick between 9 to 5, Monday to Friday.*”
- Another person commented on the complete loss of a local GP practice from their area, “*we have lost our service in Forkhill.*” He/she alleged there was no local consultation about this, no other service had opened in its place and local people were effectively receiving a lesser service.
- Many perceived it to be difficult to get an appointment. Although some people felt that there should be open surgery at certain times of the day, others were not convinced this would solve the problem. As one person said, “[At my local surgery they] *...don’t have an appointment system... have to be there early... go in and give name and wait for anything up to two hours... if there is a queue and you get to the end of the queue and it is a quarter to two, and they close at a quarter to two... refused access to the doctor.*” It was felt that any such system should be better managed.
- The out of hours GPs’ service was also rated as poor. One person felt it was not cost effective to use emergency services in this way. He/she felt “*it would have been cheaper for her [the doctor] to come out than send out an ambulance.*”
- Another person felt that ambulances in general take too long to reach their destination in rural areas. He/she felt that there should be more provision in this regard.

- Another person felt that GPs had become overly resistant to carrying out home visits. This particular individual alleged that when he/she had a sick relative at home it “took four people to convince the doctor to come out” i.e. the GPs initial advice had been to send the patient to hospital. He/she felt, “you shouldn’t have to go through all that to get a doctor out.” However, another person presented a different point of view, “the way they [GPs] look at it is, if they come out they can only deal with that one person, whereas if they don’t they can deal with a whole lot of people.”

Access to female GPs particularly difficult...

- One person considered that access to female GPs was especially problematic. It was explained that in one surgery, the female GP only sees patients on Thursdays. He/she claimed that in this situation, “you can’t get seeing a female doctor... booked solid for three weeks”. One person described how when she felt a lump on her breast she could not wait three weeks to see a female GP. Instead, she went to Action Cancer.
- A number of people took the view that some patients simply prefer to consult with a female GP, irrespective of whether the issue was related to female health or not. As one person said, “...[there are] some people who go don’t want to see a male doctor... even if they [the patient] have a cold!”

Regular attendees...

- Some people claimed that there were patients in their surgery who, it seemed to them “get into a habit of going to the doctor... the same people go every week.” As they saw it, a considerable proportion of GPs time was being consumed on relatively minor ailments. They felt that this, in part, accounted for why it was difficult to get an appointment.

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.*

Receptionist...

- It seemed to some that the receptionist was a barrier to access. As one person put it, “if you get past the receptionist, you’re okay.”
- Several participants appeared to object to having to tell the receptionists why they needed to see the GP. There was a general sense that a receptionist was not medically qualified and therefore it was not appropriate that they should be determining whether or not a condition was urgent and consequently, whether an appointment with the GP was necessary. One person summed this up by saying, “I don’t think you should have to tell the receptionist what is your trouble... you shouldn’t have to say what is wrong with you, I think that should be between you and your doctor”.

- There was a call for a general improvement in receptionists' attitudes. As one person said, *"it seems to be they [receptionists] are not particularly patient-friendly... the receptionist and support staff... it is a general feeling you get... there is this barrier, it is as if they are the gate keepers... that is as far as you will go and no further... which isn't very good for your health if you are not feeling particularly well anyway. It is something that needs to be addressed with this new training coming on board."*

GPs...

- Some described the GPs' attitude as *"very good"*, but there was a general sense that patients feel rushed and processed. It seemed to some that the service had become impersonal. As one person commented, *"[GPs are] pushed for time... don't know who their patients are... don't have the time to spend with the people... they can't talk to them [their patients]...not very personal."*
- One person felt that trying to provide a service within such tight financial constraints meant that everyone was feeling the squeeze, *"it has to do with their [the GP practices'] budget [they] can only spend ten minutes with each patient"*
- A few people indicated that their GP advises them to make a double appointment if the patient needs more time to discuss their issues.
- One person indicated that having time for patients was crucial. He/she alleged that one GP was *"so popular [because they] make time for people."*

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...

- Those consulted perceived that, *"people [who] are very articulate and would know, would have access to getting information... would be very demanding and would know how to handle a GP [would get a better service] ...the rest could maybe be fobbed off very easily."*
- They also felt that *"people who have money"* and can *"make private appointments"* got a better service. There were differing views on this. Some felt that it was fundamentally *"unfair... person with money... when the ordinary... person goes in has the same problem, cannot see a doctor and has to go on a waiting list [for] six months... or a lot longer."* Another person took the view that this represented personal choice. As he/she put it *"that [the option to go private] is fair enough, if you are prepared to pay for it, I mean you cannot blame the system for that."*

Lesser service...

- A few people felt that elderly people received, or were at risk of receiving, a lesser service from GPs unless they had an advocate to speak up for them. It seemed to them that older people were perceived by some of the medical profession as spent and not worth investing resources on, “*they [elderly people] are classed as old, so if they die, well they have lived.*” They also felt that today’s older people have a greater reticence about using a GP than today’s younger people. As one person put it, “*that generation... didn’t go to the doctor... you didn’t annoy them... a lot of elderly people are the same... don’t bother them [GPs] out of hours.*” It was felt that as a result of both these factors, some older people were at risk of receiving a lesser 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:

- Provide more GPs – Felt that currently there were too many restrictions on the budget for GP services and time with individual patients was very limited.
- Have open surgery at certain times of the day /week. Ensure that such a service is properly managed and patients’ expectations from such a service are properly managed.
- Provide more access to female GPs.
- Provide a better out-of-hours service.
- Provide evening surgery and Saturday surgery.
- Faster ambulance service for rural areas.

4.1.2 SECOND PRIMARY CARE SERVICE – ALLIED PROFESSIONS TO HEALTH

Those consulted commented on a range of services under this heading.

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

- Poor access to speech therapy – one person indicated that a family member had had a stroke and that this person needed speech therapy. However, he/she alleged that after the person left hospital “*many appointments were cancelled*”, by speech therapy, the day before the person was due to attend. He/she speculated that a member of staff was off sick and that there was no-one to replace him/her. It was felt that such a consistently low level of service was unacceptable. He/she believed that in this situation someone without an advocate could be easily overlooked.
- Poor access to physiotherapy – as one person said “*in relation to physiotherapy the list is outrageous... months and months and months... I think that sort of service should not be in the hospital, it should be community based, it needs to be where people feel confident about going to.*” It was felt that access to

physiotherapy should be prioritised differently so that new patients are given some access early on to help them begin an exercise / recovery regime i.e. rather than waiting for three months with no intervention. Another person indicated that one of his/her relatives only received physiotherapy three months after a stroke. He/she alleged that by then their relative had “*nearly contracted*”.

- Poor access to community psychiatric services – although not part of allied professions to health) one person commented on community psychiatric services. He/she felt that more community psychiatric services were needed in rural areas, the current service was too centralised and that there was insufficient resources to cope with the mental health problems in the area. He/she perceived that more community mental health day care services were needed and that such provision should be based on a social model of health. He/she also felt that there was a particular shortage of services for young people (16 – 18 year olds) with mental health conditions. It was felt that the priority areas were resources to deal with suicide prevention, attempted suicide and bereavement.

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.*

These topics were considered together.

- Physiotherapy – one person felt that some of the physiotherapy staff had an uncaring attitude. He/she claimed that when a family member needed a walking aid, “*they [the physiotherapist] just gave her [the family member] a walking aid, didn’t show her how to use it... didn’t adjust it or anything.*”
- Occupational Therapy – another person described a situation where his/her grandmother had been provided by the hospital with a chair. However, the grandmother found it very uncomfortable to sit in and the chair was much too big for the room they normally sat in. Her preference was therefore to have the chair removed. However, occupational therapy allegedly said that “*services [home help] was going to be pulled out if the chair wasn’t used... insisted that the chair was used... their staff getting their back hurt*” lifting the grandmother from her wheelchair to any other chair. In the end, this family had to lift their grandmother from her wheelchair into the chair themselves.
- Speech therapy – one person perceived that in relation to speech therapy:
 - access to the service was very poor;
 - assessment of the patient was too superficial; and
 - they underestimated what children, in particular, were capable of and assigned them exercises well below their level of competence.

He/she felt that all of this effectively slowed down the child's progress with speech therapy.

He/she also believed that speech therapists adopted a superior attitude with parents, *"they think they are better than you."* It was argued that speech therapists needed to update their professional knowledge on what new techniques and approaches are now possible, especially with children. In their words, *"in two years [my child has had]... ten sessions of twenty minutes... they come in and put toys down... it's just patronising... seem to give up on children."*

- Lack of multi-disciplinary working - According to one person, part of the problem with these services is the lack of communication across the various disciplines. In his/her words, *"everyone is in their own little silo... no multidisciplinary working, or there is very little of it and I think the patient is suffering at the end of the 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*

Same service...

- Some people thought *"everybody is in the same boat when it comes to therapy service."*

Better service

- There was a general feeling that those who shout louder get a better service. One person mentioned the growing number of parents groups and how collective action was achieving improvements in some services.

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 allied professions to health:

- Provide more therapists.
- Make the services more patient-centred.
- Re-introduce a caring attitude. One person felt that *"the humanity has gone out of it [professions allied to health] ...everyone just after money"*, *"everybody now is just a number."*
- Improve inter-disciplinary communication and working. As one person put it, *"one crowd doesn't know what the other crowd is doing... no communication."*
- Provide a one-stop shop option for patients with multiple needs, for example, provide occupational therapy and speech therapy appointments in the same location on the same day if need be.
- More community psychiatric services are needed in rural areas.
- Decentralise community psychiatric services.

- Provide more community mental health day care services based on a social model of health.
- Provide more community psychiatric services for young people (16 – 18 year olds) with mental health problems. The priority areas were thought to be resources to deal with suicide prevention, attempted suicide and bereavement.

4.2 SECONDARY CARE SERVICES (HOSPITALS)

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

Access considered to be poor...

- Some felt that the level of access depended on individual GPs and whether or not they refer patients.
- Others felt that hospital access was very difficult for people who did not have cars. Even if someone had a car, the parking was described as “*terrible.*”
- Ambulance transport was considered very inconvenient, “*if you depend on an ambulance... lifted at 8... [your] appointment is at 10... [and] you're left to 6 o'clock*” to be taken home. There was a sense of being abandoned. One person added that during this time “*you are never offered a cup of tea.*”

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 topics together. They made the following points:

Nurses...

- The attitude and helpfulness of nurses was generally thought to be good, “*couldn't do enough for you*”
- One person felt that the attitude of the staff and the quality of the care on “*the children's ward is very good.*”
- Others felt that nurses today were preoccupied with mundane paperwork rather than patients. In the words of one person, “*an awful lot of time is taken up with paperwork... bureaucracy... the requisitioning of equipment... too much emphasis.*”
- Another person considered that there was “*too much emphasis on people getting degrees... if they [nurses] just did what they were supposed to do which is nurse*”

people, I find they have no time for their patients.” He/she perceived that some nurses were more concerned with their personal career development than patient care. Commenting on the current drive for additional qualifications and the limited number of senior posts available, he/she concluded, “not everyone can be managers”.

Consultants...

- Many felt that Consultants had poor attitudes to their patients. One person, reflecting the general view of the group said, *“please don’t get me started on Consultants!”* He/she described a situation where the GP had referred his/her young child to a Consultant to have an in-growing toenail removed. When they arrived for the appointment the Consultant allegedly said, *“I don’t do this for children under twelve.”* The parent insisted that the GP had referred the child to him. According to the parent, the Consultant refused to carry out the procedure and *“slammed the door closed”* on them. The parent reported the incident to the GP who agreed to carry out the procedure. Commenting on the Consultant involved, the parent said, *“I don’t know where that man got his manners from... he had the child scared stiff”.*
- Another parent described how he/she brought his/her sick child to hospital. According to the parent, they *“sat for three hours.”* It was alleged that, the Consultant to whom they had been assigned said that he/she had kept them waiting because he/she *“thought the child was pretending.”*
- Another parent described how he/she rebuked a Consultant whom it was claimed started stitching a wound on the child before the local anaesthetic had taken full effect. The parent claimed, *“the child was screaming the place down.”* According to the parent, the Consultant lost his/her temper at being challenged and *“flung the trolley [with the surgical instruments] across the middle of the room.”*

n) <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.</i>
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Better service...

- Those consulted felt that patients who paid privately got a better service and faster access to services.
- Many felt that people received a better service *“if you know your rights and services.”*

Lesser service...

- Some felt that elderly people could receive a lesser service *“if they have no-one to speak up for them.”*

- One person pointed out that he/she felt that people from different areas were treated differently depending on whether the area was perceived by hospital staff as affluent or disadvantaged. One person described how when he/she attended hospital for a mammogram he/she was asked for a home address. He/she felt that the staffs' attitude towards him/her changed when it was discovered he/she lived in a disadvantaged area. He/she referred to this as the "Oh!" factor – as in "oh, you're from" He/she felt that the staff were looking down on people from that particular area.

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:

- Improve the bedside manner of Consultants.
- Give patients more time with Consultants.
- "Go back to the old way... matron on the ward... done her round... made you feel like a person... you [a matron] had to know about that person... ward manager... more paperwork."
- Mixed feelings about whether or not there should be less private patients. Some felt that the waiting lists for certain procedures and services were so long that patients "are pushed to go and get" private treatment. Some felt that private patients "cause discrimination" (i.e. ideally those with greatest need would be seen first but having the option to go privately means that those with the ability to pay get seen first) and they regretted this effect. However, as one person remarked, "some people go down hill on a waiting list... would have been dead if... not gone privately."

4.3 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?

Thought to be largely ineffective...

- Some people felt that advertisements related to addiction issues, "sometimes annoys people all the more... people have to be ready to change." They felt that smoking was "very addictive" and that health promotion information alone was not enough to dissuade someone from smoking.
- Some felt that alcohol abuse and the effect on families in particular was more harmful than smoking. They felt that there should be more emphasis on this.

- A few people expressed anger at, what they saw, as mixed messages from government. It seemed to them that parts of the current benefits system enabled some addictions and failed to support some illnesses. One person claimed, “*if you’re an Alco [alcoholic] you can have DLA [Disability Living Allowance]... if you’ve got cancer you can’t get DLA.*”
- A few felt that the challenge was to “*get through to children.*” They felt that the health promotion messages were “*not getting through to boys to slow down [speeding].*”

4.4 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...

- The problems mentioned were:
 - Obesity.
 - Increase in the prevalence of diabetes.
 - Inactive lifestyle of today’s children. As one person put it, “*children don’t know what their two legs are for.*”
 - Underage drinking. One person commented, “*it’s [alcohol] so easy got... ten, eleven, twelve year olds... go into any pub and they’re getting served.*”
 - Drug abuse.
 - Smoking.
 - Cancer.
 - Heart disease.
 - Services for elderly people and disabled people – one person in the group perceived that the staff providing these services “*want more money but not doing as much... medicine, health and education... need to work together.*” However, he/she felt that home helps were not getting paid enough, “*the ones at the top are getting paid loads.*”
 - Potential for litigation – using the example of the home help service, some people commented that managers are becoming increasingly concerned

about the health and safety of staff because of the increase in cases being taken against the health authorities.

- The increase in the level of suicide amongst young people.
- Aids.
- Bullying in school.
- Parents putting pressure on their children to achieve e.g. academically, musically, in sport etc. Could be affecting the mental health of the child.

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?*

Hip replacement...

- One person indicated that he/she had paid for a family member to have a hip operation done privately.

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

Varied views...

- One person felt that if complaints are made that the health authorities “*will do their best.*”
- Several others were sceptical, “*not great*”, “*patchy*”, “*it depends who you are, where you are and what you have*”, “*Community [medical services] is poor [at dealing with complaints] ...hospital ...I find it very good.*”

5. PEOPLE IN A DISADVANTAGED NEIGHBOURHOOD

FOCUS GROUP:	PEOPLE IN A DISADVANTAGED NEIGHBOURHOOD
VENUE:	GORTALOWRY HOUSE, COOKSTOWN
DATE	14 th APRIL 2004
NUMBER OF PARTICIPANTS:	9

Profile of Participants			
		Number	%
Sex	Male	-	-
	Female	9	100
Age	Under 18	-	-
	18-24	1	11
	25-44	5	56
	45-64	2	22
	65-74	1	11
	75+	-	-
	No Answer	-	-
Disability	Yes	3	33
	No	6	67
	No Answer	-	-
Dependent Children	Yes	5	56
	No	4	44
	No Answer	-	-
Other Caring Responsibilities	Yes	2	22
	No	6	67
	No Answer	1	11

5.1 PRIMARY CARE SERVICES

The group chose to discuss:

- GPs; and,
- Health Visitors.

The feedback was as follows.

5.1.1 FIRST PRIMARY CARE SERVICE – GP

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

Access perceived as difficult...

- A few thought that access was easy. One person remarked that at his/her local health centre “*If you ring at 9 [am], you will get seen that day.*” However, he/she conceded that he/she had not tried doing this.
- Many felt that it generally took too long to get an appointment. Some indicated that it took seven to eight days to get an appointment with their own GP. Others said that they generally had to wait up to two weeks to see their own GP. If a medical matter was urgent, some people opted to see a locum. However, many regarded this as unsatisfactory. One person said, “*I find this frustrating.*” They would have much preferred to have “*continuity*” of their consultation with their own GP. They disliked having to explain their situation / condition to locums “*all over again.*”
- Some parents shared the view that, “*it’s not so bad if you’re an adult. But if you have a child, a rash could be meningitis.*” In which case, they considered that waiting a week or two for an appointment was not acceptable.

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

Patient care in the waiting room...

- One person thought that the quality of patient care in the waiting room was poor. He/she claimed that as a parent having gone to the local clinic with his/her sick child, they had to wait an hour for their appointment, during which time the child

vomited in the waiting room and, it was reported, the staff offered them no help even in terms of cleaning up.

Quality of Service / Attitude of GP...

- There were mixed views on the attitudes of GPs and the overall quality of service.
- A few felt that GPs mainly had a good attitude towards their patients and that generally GPs take their time with patients. One person shared his/her experience, *“if you give them [GPs] enough information, they are prepared to listen to you, I don’t feel pressured as you say, to get in and get out as quickly as possible... they [the GP] have a good personality.”* One person also remarked that his/her GP draws diagrams as necessary to aid understanding and he/she found this helpful.
- Several others however, felt that their GPs rushed them through their respective consultations. As one person commented, *“I think it’s [the duration of the consultation] as quick as they can get a prescription to you.”* Another person claimed that the GP writes a prescription *“while he’s talking to me... before I can explain my situation.”* One person perceived that any diagnosis, which could ensue under such conditions, was, in their opinion, at best, superficial and at worst, possibly flawed. In his/her words, *“I feel I might as well not have bothered... [I] didn’t get to explain all my symptoms.”*
- A few people empathised with the pressures they perceived GPs to be under, *“...too many patients to see... too much administration.”*

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 getting a better service was linked to *“who you know.”* They felt that this simply reflected everyday life. In the words of one person *“it’s natural.”* To illustrate this point, one person claimed that she knew a midwife who became sick when she was pregnant. Allegedly, she and the midwife suffered from the same type of sickness during pregnancy but when the midwife became sick she was given steroids to treat it. The woman attending the focus group said that she was not offered steroids and was told that her only option was to go into hospital. As a result she perceived that the midwife, *“got them [the steroids] because of who she was...it is obviously who you know.”*

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 GP services:

- Reduce the waiting time to get appointments.

- Ensure that patients are taken on time for their appointments. As one person said, *“if the appointment is at half one... you shouldn’t be [still] sitting at a quarter to five.”* The group felt this was especially important for people who do not have access to their own transport and / or children to look after. One person indicated that there should be more attention given to the adverse practical effect on people’s lives of delayed appointments, *“they don’t take into account that people have no transport... or someone with a child [with them at the surgery] and three at home.”*
- Have nursing staff available to carry out routine procedures. Some people in the group commented that people would wait for up to an hour to see a GP to have a blood sample taken and that this was not convenient.
- More home visits. Those consulted said that it was *“hard to get them [GPs] to come out [to do a home visit]”*. In the words of one person, *“they [GPs] don’t take into consideration people... who genuinely need house calls.”* They wished to see more flexibility with this, especially as regards home visits to elderly people.

5.1.2 SECOND PRIMARY CARE SERVICE – HEALTH VISITOR

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

Access perceived as good...

- Most commented that, in general, access to health visitors is *“fairly easy.”* People seemed to appreciate the prompt return of phone calls. One person said, *“if you ring up the practice, they get back to you the same day.”*
- However, some commented that having to wait for lengthy periods of time at baby clinics was an issue *“you could be waiting two hours [to be seen]...child has to be patient”*

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

Mixed views...

- There were mixed views about the overall quality of the service.
- One person felt that the service was good but that health visitors should visit more frequently, especially first time mothers, to either assure them that their child’s development is normal or to guide them to other support services if they / their child needs them. As one new mother indicated, *“my daughter was not eating well or speaking well... would like someone to allay my concerns... but as a new mother... don’t know the processes.”* This person felt that, in her case, she could have discussed these issues with a health visitor. She was grateful for the reassurance she received, *“if you’re worried about something they could listen and advise you what course of action to take.”*

- Another person felt that health visitors were overly cautious (“*very good... a bit too good*”) about a child’s development. He/she claimed that his/her health visitor had asked some general questions about the family’s history of health and the person had replied, “*there is a small history of squints.*” He/she claimed that upon hearing this, the health visitor “*immediately had...[his/her] child down on the list*” to be checked for squints, even though the child was not showing any signs at that stage of having a squint. As he/she put it, “*...the next thing I knew I had an appointment at the opticians [for my child].*”
- One person thought that, because of the unfamiliar surroundings in which some assessments take place, that his/her child sometimes behaved in a way that does not truly reflect the child’s abilities. He/she therefore felt that, at times, children could be assessed as having a lower ability than they actually had. As one mother put it, “*you know your child can put the puzzle together*”, she had witnessed the child doing the puzzle with ease at home and yet when the child is at the clinic, the child seems unsettled and does not put the puzzle together. She added, “*if they [my child] were in their own environment it would maybe be easier, it wouldn’t be a threat to them*”. However, it was felt that health visitors were too quick to conclude the worst. “*if the child doesn’t react the way the health visitor thinks they should they [health visitors] automatically think something is wrong.*” Many of the parents felt that in some situations there was a simpler, innocent explanation.
- Another person made a similar comment in relation to hearing tests. He/she felt that a child could be easily distracted by something else during a hearing test but that if the child did not react exactly according to what the health visitor regarded as a ‘normal’ pattern / profile / behaviour, then the health visitor was too quick to conclude there was a problem.

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 good attitudes...

- Most felt that the majority of health visitors had an “*okay*” attitude, “*very good*”, “*very helpful.*”
- One person, however, indicated that he/she felt patronised at times, “*...some of them think you’re stupid.*”
- Another person felt that some health visitors come across as theoretical rather than practical. In the words of one person, “*...some have read a text book.*” As far as this person was concerned, any such advice did not seem to be grounded in reality, “*especially when they [the health visitor] have no children of their own.*”

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.*

Same service...

- Those consulted felt that given the structured nature of the visits and assessments that everyone gets the same service. Summing up the general view of the group, one person said, *"I don't think anybody gets any special treatment."*

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 health visitors:

- Enable mothers to speak more openly about their concerns / need for other types of support, one mother was concerned, *"can you trust them [health visitors]?"* She went on to add, *"you would be afraid to say you were depressed"*. She perceived that *"a lot of kids have been taken away because the parent has said they are slightly depressed."* Therefore, whilst a mother may need extra support for depression the risk of losing their children would put them off saying openly that they were depressed and / or seeking help.
- Health visitors to visit more often at key stages. One mother suggested, *"they [health visitors] would need to be coming when the child's teething or crying [a lot]."*
- Health visitors to visit once a month. One mother suggested that health visitors should *"call once a month for the child's first year"*. They felt that this was important for reassurance, especially for first time mothers. As she put it, *"you might think you're over reacting about something, but it puts your own mind at rest if you can discuss it with them."*
- Another person suggested that health visitors should be visiting more often if there was any reason to suspect *"child abuse / battering."*
- Some mothers would prefer *"if they [health visitors] called once a month or you [the mother] could go up [to the baby clinic] on a certain day a week... just drop in... could go and see a health visitor [if you had concerns]."* They pointed out that some health centres have this facility but it is not convenient for mothers, *"you wait 2 hours [before you are seen]."* They suggested that having the ability to book an appointment, *"even for 5 minutes"* would be very helpful.
- Provide more support for one-parent families – One person felt that health visitors should provide more support to lone parents, especially with their first child.

5.2 SECONDARY CARE SERVICES (HOSPITALS)

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

Concern over possible closure of local hospital...

- Many in the group expressed concern over the possible closure of their local hospital. In the words of one person, “...people in this area... mid-Ulster... feel very vulnerable.”

Difficulties with appointment times...

- Some people commented on how difficult it was for them to attend Belfast based hospital appointments first thing in the morning. For example 9.10 a.m. when they had no transport of their own. The journey was very convoluted and long. They remarked, “they [those issuing the appointment times] don’t think of the practical aspects... where the person lives.” Another person remarked, “they [a Belfast-based hospital] send me a 9 o’clock appointment... I am coming from Cookstown through rush hour traffic [in Belfast].”

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 subjects together. They made the following points:

Nurses are overstretched...

- Several people perceived that there were not enough nurses and those that were there were overworked. As one person said, “some of them [the patients] are neglected... because there are not enough nurses, there is not enough staff”. Another added, “they [nurses] can’t cut themselves in half... maybe someone needs an injection at 12 o’clock but they [the patient] don’t get it until 3 [o’clock]. If someone is diabetic, they need it [the injection] at 12 o’clock.”
- Another person empathised with the nurses and commented on what they perceived as understaffing in general. As he/she explained, “the patients take it [the lack of attention] out on nurses [but] it’s not the nurses fault, they are doing their best.”

Uncaring attitude of some Consultants...

- One woman in the group claimed that her son had died shortly after birth. According to her, the Consultant attending to her visited her in her bed the following day and referring to the death of her child said, *“have we got over our little disappointment yet?”*

Lack of beds available...

- A few people remarked on the lack of beds and criticised the use of trolleys.

Shifts too long...

- There was also a perception that the shifts which nurses and hospital doctors are asked to work were too long and were potentially posing a serious risk to care and well-being of some patients. One person remarked on *“doctors on 16-hour shifts... should be broken up more... if they have to perform an operation... could be dangerous.”* One member of the group alleged that she had been admitted to hospital to have an caesarean emergency section performed. She claimed that the doctor who performed the procedure *“had been on duty 24 hours”* before that.

Loss of caring approach...

- There was a general sense that what was once a caring profession had now become an overstretched, overworked service. One person said, *“I blame the government... the government has put them [nurses] under so much pressure... all they [hospital staff] are there for is their pay... don't have time to care.”*
- One person in the group who had consented to take part in hospital based research in relation to bowel cancer, indicated that he/she had asked for a sedative before the procedures, which were part of the research, took place. He/she claimed that his/her GP had agreed to the need for a sedative, but the hospital staff would not provide the sedative unless the patient insisted. He/she felt that given the discomfort of the procedures and the fact that he/she had volunteered for the research he/she should not have had to insist. He/she perceived that the hospital resisted because there was no room to accommodate him/her in the hospital while the sedative wore off.
- Another person described how when his/her uncle was admitted to hospital *“the nurses did not have time to feed him”* despite the fact that he was totally blind and had senile dementia. He/she claimed that when visiting they discovered that his meals were being simply put down in front of him and when the meals were not eaten they were taken away again. He/she commented in astonishment, *“he [my uncle] couldn't see it! [his meal].”* He/she was amazed that something so obvious could be overlooked and that such a highly dependent patient would be neglected in this way. When a relative started to feed their uncle during a visit he/she claimed that he ate so gustily it seemed to them that the man had been starving.

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.*

These two topics were considered together.

Better service...

- A few of the participants commented that people could get a better service depending on whom they knew.
- One person told us that they knew a child whose parent worked in an x-ray department. He/she alleged that when the child fell in the playground that the parent simply “walked in” to the x-ray department with his/her daughter and she was x-rayed immediately.
- Another person alleged that when women are being booked in to hospital to give birth that “some people get a side ward [rather than an open ward] ...if you know a mid-wife.”
- Another woman told us that her baby was due close to the time of her sister’s wedding. She was keen to have the baby ahead of the wedding. This woman claimed that she spoke to the lead Consultant in charge of births at the hospital [the “head boy”] and told him she wanted to have her baby before sister’s wedding and asked him if there was anything he could do. She claimed that he told her to come in to the hospital and “let on there is a pain in your back.” She did not have such a pain but did what he suggested. Her baby was delivered the next morning.
- Some other people felt that a patient received a faster service if they arrived in an ambulance. As one person commented, “if you come in an ambulance ... seen before other people... before people in their own transport.”

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:

- Provide more nursing and medical staff. As one person put it, “go back to square one and that is the doctors and nurses in the hospitals.”
- Provide more places to study nursing and medicine rather than Queen’s University Northern Ireland.
- Cut down the waiting lists.

- Cut down on the “*red tape*.” One person felt that at the nursing stations too many nurses were spending time writing (i.e. rather than caring for patients). One person perceived, “*administration, for God’s sake, there is no call for half of it... all paperwork.*”
- Provide more hospitals – As one person said, “*you [a patient] can’t be travelling miles and miles when it is an emergency.*” Hospital locations need to take into account where people live.

5.3 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.
- Generally, such campaigns were thought to have a positive long-term effect but minimal immediate effect.
- One smoker in the group indicated that the stop smoking campaigns had no effect on him/her. As he/she commented, “*I never took them under my notice.*”
- Another person remarked on how it had now become anti-social to smoke. He/she felt that fewer young people smoked nowadays compared with several years ago, “*it’s not the thing to do anymore.*” He/she felt that health promotion campaigns have made some contribution to this.
- A few were not convinced of the merits of strenuous exercise. Referring to the recent deaths of a high profile football player and rugby player, one said “*...some fellas very fit... but still died... is pushing yourself to the limit necessarily good*”.
- Another participant seemed to believe that illness was so random that it was difficult to know what health promotion information would protect people. As he/she put it, “[some] *people die with cancer and they never smoked.*”
- Another person commented that the role of health promotion was preventative, “*it’s good that the government is promoting health... [in the short term] the money is taken out of something else... [but] we will have less of these problems [in the future]... its all a learning process.*”
- One member of the group indicated, “*in school, we have healthy eating weeks... it’s worthwhile... saves people from getting these problems [obesity, bad oral health etc].*”

- One person felt that the message about not overusing antibiotics had now got through to many people. Referring to what he/she perceived as a change in public attitudes and behaviour, it was felt that, “*people have learnt from it.*”
- A few felt that health promotion was “*better than nothing*” (i.e. no promotion).

5.4 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...

- Concern about closures in mid-Ulster – Some people in the group felt that since the population was growing in mid-Ulster and people are generally living longer that there should be hospital facilities in mid-Ulster. There appeared to be a dread of having to travel to Antrim or Craigavon for treatment.
- Concern about modern diet and lifestyle. One person on the group perceived that the older generation were healthier than today’s young people, “*they [older people] didn’t have the drugs... junk food.*”
- Concern that, as a society, “*we are too clean.*” In the words of one person, “*children can’t cope with germs... don’t get a chance to build up their own immune system.*”
- Concern over waiting lists - Especially if the local hospital closes and a local waiting list is merged with another hospital.
- General concern at the workload of nurses and doctors and the loss of a caring approach as the, “*health service is so overstretched.*”
- Concern about overall funding. One person wondered for how long the present NHS could continue and speculated that future provision would be largely private.
- Concern about the perceived increase in the prevalence of cancer and other diseases, for example, a recent mumps outbreak.

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?*

Paid privately for operation and home care services...

- One person indicated that twelve years ago, he/she was on a waiting list to get his/her tonsils out. After deciding to go privately he/she was allegedly “called the next [following] week.”
- Another person told us that he/she paid for a private home help for his/her mother when the regular home help was not allowed to do cleaning.

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

Generally don't complain and not happy with how complaints are handled...

- Most people indicated that they would not bother complaining. They feel “put off” by the process involved and the dismissive and patronising attitude of some staff. One person felt that some hospital staff “fob you off” or try to create the impression that “they are so much more intelligent than you.”
- In some cases, those who have experienced traumatic events were too emotionally overloaded to consider complaining.
- One person in the group indicated that after his/her son died in hospital he/she wanted to find out more about the cause of death. When he/she told the Consultant involved that they would like a second opinion on the cause of death, the Consultant allegedly asked in an accusing manner, “are you under estimating my capabilities?” The person concerned remarked, “I felt we couldn't get a second opinion... didn't know how to go about it.”
- Others felt that there was no point complaining because they believed that, “they'd [the medical profession] back each other up... like the secret service.”
- Hospital staff allegedly told one woman in the group that her son died before being born and not after. The mother concerned contested this on the basis that her friend allegedly heard the baby cry from outside the delivery room. In addition, she alleged that she was not given a reason for the death. She felt that she could have brought a case against the hospital but added “even if I [had] won that case it wasn't going to give me what I had lost.”