



**HEALTH AND SOCIAL SERVICES COUNCIL  
PATIENT CLIENT COUNCIL  
CONSULTATION**

**FEBRUARY 2009**

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## **INTRODUCTION**

- 1** Disability Action is a pioneering Northern Ireland charity working with and for people with disabilities. We work with our members to provide information, training, transport awareness programmes and representation for people regardless of their disability; whether that is physical, mental, sensory, hidden or learning disability.
- 2** 21% (369,390) of adults and 6% (105,540) of children in Northern Ireland has a disability and the incidence is higher here than in the rest of the United Kingdom. Over one quarter of all families here are affected.
- 3** As a campaigning body, we work to bring about positive change to the social, economic and cultural life of people with disabilities and consequently our entire community. In pursuit of our aims we serve 45,000 people each year.
- 4** Our network of services is provided via our Headquarters in Belfast and in three regional offices in Carrickfergus, Derry and Dungannon.
- 5** Disability Action was approached by the Health and Social Services Council to assist them in consulting with groups and individuals on the new Patient Client Council.
- 6** Following discussions with the Health and Social Services Council Disability Action received funding to engage with individual disabled people to determine their key issues and their envisaged potential impact of the new PCC.
- 7** The Health and Social Services Council wished to consult as widely as possible on the policy throughout Northern Ireland and, in particular, ensure that all four Health and Social Services Boards were covered.

## THE PROCESS

- 8 Disability Action has 134 member groups throughout Northern Ireland and each outer office holds a local database. All of these groups were contacted by letter inviting them to take part in a consultation event in an area which was nearest to them.

## 9 LOCATIONS

**Date:** Thursday 13 November 2008  
**Time:** 10.30am – 12.30pm  
**Venue:** Disability Action  
Portside Business Park  
189 Airport Road West  
Belfast BT3 9ED

**Date:** Thursday 13 November 2008  
**Time:** 2.30pm – 4.00pm  
**Venue:** Disability Action  
6 West Street  
Carrickfergus BT38 7AR

**Date:** Friday 14 November 2008  
**Time:** 10.30am – 12.30pm  
**Venue:** Disability Action  
58 Strand Road  
Derry BT48 7AJ

**Date:** Tuesday 18 November 2008  
**Time:** 10.30am – 12.30pm  
**Venue:** Killyhevlin Hotel  
Killyhevlin  
Enniskillen BT74 6RW

**Date:** Wednesday 19 November 2008  
**Time:** 10.30am – 12.30pm  
**Venue:** Willowbank Resource Centre  
Carland Road  
Dungannon BT71 4AA

## **10 PUBLIC SEMINARS**

The five public consultations followed a similar agenda:-

- Introduction – Disability Action
- Patient Client Council Presentation
- Open Discussion/Forum – Disability Action
- Close – Disability Action

**11** Each seminar was attended by two Disability Action staff.

**12** Each participant was given travel expenses for attending.

**13** The response rate to the public consultations was quantitatively smaller than anticipated however the seminars were attended by experienced service users who provided lively and informative debate. The qualitative findings of the consultation exercise will be an invaluable resource to inform future PCC policies.

## **14 FEEDBACK**

Feedback was gathered by a notetaker and a dictaphone to ensure accuracy. Participants were asked prior to the open forum if they agreed to the taping of the discussion. All agreed with the proviso that information would be deleted after report completion.

In the interests of transparency, accountability and plain language the feedback is reported chronologically and for ease of reference in plain language. Disability Action has listed the comments under 12 headings. Disability Action has kept the text as true to the spoken word as possible.

## **15 BELFAST FEEDBACK 13 NOVEMBER 2008**

### **Appointments**

- In relation to the PCC there's an issue about appointments being made on merit. I already know that there are very few disabled people participating in public life – so if part of the merit is “have you been involved before?” the risk is disabled people are far down that pecking order.
- If it's qualifications – qualifications rule out people with disabilities immediately.

### **Complaints Procedure**

- I'm actually in the process of a complaint at the moment. I just started it off three weeks ago. I wasn't even aware that there was a complaints procedure. This is one of the things that I discovered. I had to go and find out myself that there was a procedure to make a complaint.
- I am very literate on the internet and I have worked in the health service for about 12/15 years. I made a complaint to the Belfast Health and Social Care Trust and eventually when I got the complaint down in writing and got it made there was lady assigned to the case. One of the things I have discovered regarding this is that they send out a lovely little book that said they would reply within 28 days of receiving the complaint, which has now turned into 42 days and when I called this person to try and get an update - they never have your case file there, never have any knowledge. They then tell you that they will call you back which they never do. I personally think is it worth making a complaint at all?
- It's like a closed shop. I would like to see the complaints system independent and as detached as possible from the health service.
- There may be a perception by people generally and many disabled people more so that when you become disabled you feel the world's

against you. They will try and fob people off and hope the complaint will go away. Rather than go away it's now going to escalate.

- I'm now going to take the complaint to the GMC. I have the right to access treatment that's available.
- One of the things required is a step by step guide on how to complain. It's ridiculous that you should have to surf the net to find this stuff yourself and even if the information is there it's not in plain English.
- It has to be user friendly and in plain language.
- Even on the website although it's plain English it can still be difficult to access.

### **Access to Information**

- Another barrier is lack of information. When a person is diagnosed with an illness they are sent home and no information is given. They should be given all the information they need. People are being ignored and there needs to be accountability.
- It's not enough to simply say, "it's on the web". Too often you are referred to the website, it would be lovely to get a fairly simple website that the ordinary person can use, because they are so complicated.
- To use the web you need to be computer literate.

### **Location**

- Regarding the locality of the Council. The Belfast Trust is up in Murray Street. There's no parking there. If you park there you will get a thirty pounds parking ticket which is a good deterrent to stop you making a complaint.

- The PCC offices need to be accessible and people should know where they are.

## **Complaints Procedure**

- When it is said that you will receive a response within 28 days you should receive a response in that timeframe even though it's only to say "clear off I don't have any further information at the moment" but not to leave people just dangling.
- What is the sense of having a policy if you don't abide by it? They would be better with no policy rather than having one that they don't abide by.
- The one good thing about having a policy is that if they don't abide by it then you can hammer them. If they have actually stated somewhere that there will be a response within 28 days, even if that response is, "we can't tell you anything more", if it's in a policy, you are perfectly right to write or email and state "your policy states, x y z and you haven't adhered to it. It's actually a complaint about the complaints procedure.
- You begin to think you are a hamster running round a wheel. Where do you go? You just want the problem sorted out.
- It's very difficult when you are in hospital and you are put back out into the community. Community care doesn't exist. Support services just are not there. That's why we are not aware of the complaints system because the amount of complaints from the community must be unbelievable. If people were to complain about all the things, I would imagine that they would need a new complaints department.
- You receive documents through the post stating that, "we welcome your views, comments and complaints, please contact us". When you contact these people the line usually goes dead.
- Complaining affects you mentally and physically. You are asking for something reasonably simple that can be resolved quite quickly.

- I am looking for a letter with a consultant's signature which would mean for me a doorway to the treatment, that I am prepared to pay for, which is not very expensive. It should be provided through the NHS but I'm happy to go the private route and get it done. I could sue the Trust as they are keeping me in a wheelchair longer than I need to be.

### **PCC Structures/Functions**

- It's nice to see a new Patient Client Council and it's going to be a new start.

### **Access to Services**

- If a care package was available in the local community that would be the main thing, because of the lack of care in hospitals.
- Recently my mother-in-law was in hospital and I was able to witness food left in front of older people and if they ate it, they ate it and if they didn't it was taken away and that could happen for days and the older person doesn't know they haven't had anything to eat.
- There has to be accountability and a care element there. They say they haven't time but they have time to talk to each other and socialise with staff. The Patient Client Council could take on the caring issues.
- The PCC need to talk to people. They need to walk into a ward unannounced and talk to the patients. Start at ground level, walk into the toilets, see if the showers etc are clean.
- Secret shopper would be a very good idea.
- The Regulation and Quality Improvement Authority (RQIA) employs secret shoppers. They can walk into a place unannounced.

## **Structures/Functions**

- What about the relationship between the PCC and the RQIA?

## **Complaints Procedure**

- There is an also an issue regarding what training is being provided regarding the complaints procedure. The risk is that it just goes into a big black hole.
- The public have to have a perception that the Council is detached from the people you complain about.

## **Structures/Functions**

- The people involved in the Council from day one need to be sincere. They need to have that within their culture and within their background.
- If you have people there that couldn't care less, the PCC are never going to go anywhere.

## **Access to Services**

- I do believe that health and social care workers do put the effort in and they do care that's why they are in the health service in the first place.
- I believe one of the biggest things is the way they are managed. I am not sure whether they are managed properly within their units. They have that much pressure they are nearly afraid to do the wrong thing and they end up doing nothing.
- In the Accident and Emergency Unit at the City Hospital they have an unwritten policy where if there is an "iffy case", they will be admitted on the ward and the consultants make the decisions. There were loads of patients being admitted on to the ward, bed blocking, and when the consultants came in they were all

discharged. Doctors and nurses are afraid to make the wrong decision and rather than decide they avoid the decision.

### **Complaints Procedure**

- I am always of the belief that if a service is delivered correctly in the first place there wouldn't be any complaints. We need to try and eradicate the need for complaints in the first place.
- When complaints are raised they need to be dealt with professionally and to ensure they are taken in a serious manner and that they are detached from the overall health service.

### **Appointments**

- No matter what your literacy is like or how many complaints you make you'll find there are certain people in any community that are happy to get involved and do things however they'll be loads of people who don't want to get involved in anything but they want everything to run fine – how do you get round that? How do you get people involved? People have to feel confident and they have to feel the atmosphere that they are in is relaxed. If they feel intimidated or if they feel that the people they are associating with is high powered; the point is having people to assist and to help.
- How much time and energy is required to be involved? It starts off one day per month and then it becomes two days and then you seem to eat, breath and sleep the thing.

### **Structures/Functions**

- When Boards amalgamate there is a tendency to reduce the funding and it is encouraging to hear that this funding may be equal or may be increased.
- They are well funded and they should do things right. It's a golden opportunity and it depends on how it's managed and set up.

- They have a chance here to get it right or get it wrong and it will depend on how they listen and who is listening.
- It's a very short timeframe between now and 1<sup>st</sup> April 2009.

### **PR/Access to Information**

- Regarding the PR exercise how are they going to do that, radio, television? When you go into your GP there are so many posters on the wall you get to the stage where you walk past them. If it is a poster campaign it has to be something that stands out.
- I think a leaflet campaign that every household will receive is a good idea. The leaflet could say that if you have a complaint call a certain number or talk to this person.
- Will the leaflet relate to each Trust area?
- They need to get a good quirky, catchy phrase. They also need a symbol that identifies it right away like the BT or Orange symbols.
- One good contact number would be a good idea and you could be dispatched onto the relevant person or area.
- A good logo with an easy to remember free phone number.
- I feel people must speak to real people rather than "talking machines". People just get fed up with talking to machines and just hang up.

### **Complaints Procedure**

- If the PCC becomes very effective they could be inundated with complaints.

### **Structures/Functions**

- Will this be a statutory body and come under Section 75 and have its own equality scheme etc?

## **Complaints Procedure**

- Every complaints body that I've worked with I have had to complain about them.
- I had an issue with motability – the DLA scheme. I was assessed and given a vehicle that I didn't want and it couldn't fit under car-parking barriers etc. I complained and got the vehicle that I wanted in the end.
- Regarding recruitment process there's always essential criteria and desirable. The applicants should be able to demonstrate that they can handle dealing with complaints over a period of time. Desirable criteria would be that they had health service background. Structures of the Trust etc.
- The PCC need to be clear of what they can and can't do when a complaint is made.

## **PR/Access to Information**

- If they get all over hurdles like the logo, point of contact etc.

## **Appointments**

- The Board is not necessarily made up of full-time employees. How many days per month are these people expected to make available? Probably at the most, two?
- What is the actual time, two days for the Board itself and then two days for working groups and now have arrived at one day per week.
- If you are working that eats significantly into the time and energy that you have available. There would need to be a reasonable time commitment and a reasonable remuneration for your time. And everybody should be paid the same.

- There could be a conflict of interest and there would need to be openness and transparency at the recruitment stage. They do have the opportunity to get it right and they are only going to get the one opportunity.

### **Structures/Functions**

- How do we know they've got it right? Is there going to be monitoring and evaluation and an Action Plan?

### **Complaints Procedure**

- Could each patient on discharge from hospital get a little card with little tick boxes? And they could then be monitored. Not everybody has a complaint or makes a complaint.

### **Appointments**

- Regarding recruitment you need a mixture of people – some with experience and some new people with vision.
- If the Board runs for 3 years – will they then lose that expertise? Will there be a roll on, a roll off? It would be terrible if the expertise was lost. You just need to make sure that everyone knows the policy.

### **Complaints Procedure**

- Regarding making the complaints easier – there could be assistance with filling in forms. For example, going to your home to get the form filled in. Having it as user friendly as possible. They need to revise what they have used to date and keep it simple.
- How to investigate and who investigates would need to be taken into consideration. I wouldn't like one consultant investigating another consultant. Need to be as independent as possible.
- Is there a cut off date for complaints like anti discrimination law?

- Must your complaint be raised within a certain amount of time?
- People need to know that this body is not making the complaint on your behalf. They are helping you with the complaint and then it is only you against the system. If the new PCC doesn't have teeth, what is the point?

### **PR/Access to Information**

- The slogan could be "PCC on your behalf"
- "PCC – there for you"

### **Research**

- What lessons have they, the PCC, learnt from the HSCC in the past?

### **Location**

- Regarding the new offices will they be in Belfast, Derry, Enniskillen, Newry with Belfast as the central one?

## 16 CARRICKFERGUS FEEDBACK 13 NOVEMBER 2008

### Structures/Functions

- Was the Patient Client Council drawn up before the recent announcements by the Health Minister regarding the Twilight services here?
- Regarding closure of residential care centres - the changes that are going to be made – it's bound to cover how the PCC would approach this whichever board area they happen to be in.

### Appointments

- I have sat on committees for the last nine years with the Northern Board and I can assure you that the Northern Board is not in the least interested. They make their own policy, they stick with that policy and they will not change. I sit on the Management Committee of the Forum here, since the amalgamation of the two Trust Boards from Homefirst to the Causeway - the fact that 75% of the Homefirst Board are now sitting on the Causeway Board hasn't changed their attitude at all.

### Structures/Functions

- We have the same Chief Executive, the same directors. Regardless of what we say it would make no difference but that's not to say you shouldn't be heard. We don't want to go in optimistically and think we are going to make a difference. In my opinion the structure of the PCC Board will not make one bit of difference.
- Will the new PCC will be a watchdog working on our behalf? We want to know has this watchdog got any teeth? Will it make a difference for the very reasons you are talking about? Boards say they consult about things, that everybody knows about it, but their minds are already made up. So what we are actually

asking, if this is a clean sheet, if this is a fresh start, how is the Council going to take on this kind of thing in the future.

- There's a consultation document coming out which was held by the Northern Board for a month before it was released, there's a few weeks left on it. Then there's another 10 week consultation coming out on the Northern Board's 20 point targets and the fact that they have to save millions over the next three years – that is actually 1 million pounds per year and 13 million is going to come out of the services in Carrickfergus.
- It's going to affect residential care and also the fact that we don't have a day centre, it was closed and was never rebuilt, that has a big bearing on it too.
- The Twilight nursing that used to be in Carrickfergus has been taken away to Antrim.
- There has been a constant drain of community services from within Carrick and we are not getting any of them back.
- I get frustrated with all these Councils and Boards that are set up, unless they have got teeth it is a wasted exercise.
- They say that they are willing and want to hear what is happening. It's alright putting these things in place, recruiting etc, but what do they actually do at the end of the day, when it's the general public who are affected by cuts. How can you influence that? If they said they are closing A, B and C in Carrick and spoke to local people they might find that A and B is ok to close however C and D they need to keep but deliver the service in a different way and save money, if they come and talk to people they could save money.
- When they are talking about the five local offices, how do they get a mandate from the people in the local areas? Would they like ideas or views on how they could actually set up a local committee of local people, a local fora, a working group, a reference group?

- A working group of local people speaking to the PCC could make a difference if they were meeting them on a monthly basis and being able to ask them what they are going to do about certain things. For example, if it was a residential closure the group could discuss that. Somebody else could ask why go to Belfast for assessments, why can't they come here? That happens a lot in rural areas where you have to go to hospital in Belfast.
- Groups like diabetes or MS or epilepsy – they should be involved in what is happening so that these organisations can bring their point of view directly to the PCC rather than trying to go to the Health Minister which is how we are doing things at the minute. You feel as if you are at the bottom of the heap trying to get to the top.

### **PR/Access to Information**

- Will they be advertising this? I never heard of the PCC. I never heard of the Health and Social Services Council either. I care for an elderly gentleman and he wouldn't know anything about that. I have to take the man from here to Coleraine to see a neurologist whereas before I used to take him to Antrim.

### **Location**

- Where are these offices going to be? How are we going to get in touch with them?

### **Structures/Functions**

- There are too many quangos and I would like to think the PCC isn't going to be another one which doesn't have any clout.
- I could see the Council being of benefit to the people of Carrick. However, if we had a Council, a sub-Council and an independent body it would be too many. What is being said by the Council is not going straight to the Northern Board, if it

doesn't gel with their policies, it doesn't happen. If it's an independent body between the Council and the Ombudsman – I would be more than happy with that.

### **PR/Access to Information**

- Regarding advertising would television not be too costly? There must be a more cost effective way? It pointless talking about cuts when you are throwing money at television advertising.
- Would the cost of advertising come from the Council itself? It's in the government's interests to get the information out eg the Charter of Rights for the Elderly. There are very few people that know about it. There are notices stuck up everywhere but not in places where they should be. You now have the right to question things and when a decision is made on what basis it is made. It's in the government's own interests to get that information to the people. The Board can be very lackadaisical when it comes to getting information through. It's the Government's duty to get it out.

### **Structures/Functions**

- Is that a role for this new PCC that they would find out about new policies and changes in policy, cuts etc and they should inform the public?
- The PCC would need to have a clause or paragraph in its mandate that says there must be inclusive dialogue before the implementation of any new policy. There must be discussion before it is implemented not after it.
- Reporting every month would be important. A feedback of some description, even if it's negative feedback. If it is not happening as positively as we would like, then we could be more assertive and say "well you have to do something or scrap it if it is not going to work". This is a chance to voice

good opinions and good ideas and monitor and evaluate the work that is being done.

### **Access to Services**

- I am a full-time carer and I would like to see a back up service. I was in a road accident a few weeks ago and it could have been serious. I was taken to hospital and kept in therefore the person I was caring for was left on their own. I do all their cleaning and all their cooking and that person can't be left at home on their own. You can't leave someone at risk. It's just phone call after phone call, they just give you another number to ring. There has to be a back up system that works very quickly. You can't rely on your family all the time. There should be a person to fill my role.
- None of us have next of kin so they can't contact anyone. Where would the person I care for go if anything happened to me, into a home?

### **Structures/Functions**

- I have found the Northern Council invaluable because they do listen.

### **Training**

- All the new people will have to be trained who will sit on this new Council.

### **Structures/Functions**

- The Council that is established needs to have a strong constitution. The ethos of the Council must be that the Northern Board understands that they are accountable and will be held accountable.

- There needs to be talks before the implementation of new policies. You need to talk about the policies before they are implemented.
- Once the PCC is set up there is nothing stopping a Forum being set up. A Forum would have a stronger voice.
- I can't understand why there are different things in different boards. Everything should be the same.
- When a Councillor sits on this Board they should come to the meetings as an individual not as a Councillor. They can't wear two hats.

### **Location**

- Antrim Hospital is very difficult to get to. I would prefer to go to Belfast because of the good public transport.
- Whiteabbey would be a good place for the PCC to have an office. There's a door to door bus stop service available. There is also a railway station and plenty of car parking spaces.

### **Community Care**

- The availability of respite care, day care etc. seems to be completely reduced or not available.
- Where is all the money going that is being saved through social workers?

### **PR/Access to Information**

- There must be information provided to the public of who the PCC are, where they are and what they do.

## **Appointments**

- On the PCC Board we should see a percentage of older people.

## **17 FEEDBACK DERRY – 14 NOVEMBER 2008**

### **Location**

- I think there is no reason why the central office should be in Belfast.

### **Training**

- Disability Awareness Training is the main thing we should be talking about. Then there would be no need for consultations like this.
- The patient can be anybody at any given time. Disability Awareness Training should be as important as child protection training and reflected in their policies.

### **Complaints Procedure**

- I had to go into theatre with my daughter who has a disability and hold her down while she was being anaesthetised, that should never happen. I felt I had so I did. I apologised even though there was no system in place to deal with this situation. Later I did make a complaint but that's as far as it went.
- People need to know where they can make a complaint. I had to make a complaint recently but because I'm involved in the Patient's Forum I knew what to do.
- What support services are put in place regarding the complaints procedure? Do they provide any assistance eg interpreters, note-takers?
- There's not too many people know how to make a complaint.

- If you are sitting in the doctor's etc you never see any information of what help is available. They keep themselves quite invisible.

## **Location**

- The location is important if they have an office at the hospital are they part of that system? How are they separated out? Where the Belfast one is there is no parking. Are there bus stops near?
- They make it so difficult for people. Banging your head against a brick wall. Every time I get over one hurdle there is another one.
- I know someone who took up an issue about parking at Altnagelvin. He had to do all that on his own with no backup.

## **Structures/Functions**

- If they want to involve the public they need to tell them what they are doing. They have used us to carry out this consultation and that is a start but the ordinary person on the street will not know.
- There should be more than 17 representatives from the community/voluntary sector.
- Some Councils had 28 people and now these go down to 17 and that is quite a smaller number.
- How representative will the 5 lay people be?

## **PR/Access to Information**

- There must be research regarding advertising – cost effective marketing.

- If they are talking about having their blue logos. They need to make sure it's appropriate for visually impaired people.

### **Community Care**

- I am a wheelchair user and every six months I have to get a sick line and my situation is not going to change. They will not give it to my mother. I have to go into the doctors. It's a nightmare also to get a new wheelchair. They always ask "does she need it?" I have to travel to Belfast for a new chair.
- If my daughter fell and needed stitches – it's an absolute nightmare to sit in casualty. She doesn't know what's going on and gets so agitated.
- My sick line is for life. It depends on your GP.

### **Complaints Procedure**

- Regarding making a complaint an accessible website is required. A link that guides you through the process and clearly explains how to make a complaint.
- The 5 local offices should have the same system. There should be consistency.

### **Structures/Functions**

- How accountable are the PCC? How open are they about what they do?
- Who evaluates the work that the PCC do?

## **Appointments**

- Regarding applying and recruitment to the PCC – you fall into the benefit trap. It depends what the fees are. People can't apply because it interferes with their benefits. If it's online, especially for people with disabilities it's harder for people with learning disabilities.
- What kind of fees are involved?
- Disabled people should apply anyway. If you have to say no because of your benefits you can ask what are they going to do about that? The onus is back on them. If a disabled person is not selected this too could be challenged.
- Where will appointments be advertised? How will it be advertised? Will the job description be user friendly? Then there is the application process. The whole system should be reviewed.

## **Location**

- The location of the offices must be accessible.
- Their office should be somewhere like the library where it's neutral and central. Every town has a library.

## **Survey**

- I received a card this year asking for my comments about the health service but the print was very small and I couldn't read it.
- What about telephoning people rather than sending people letters.

## **Structures/Functions**

- If 5 local offices are to be effective they really need to look at how they are going to gather information. If people are brought

along and asked what their opinions are but if they don't hear and don't receive feedback people will fall away.

- If it is to be effective and meaningful these structures have to be done really well. So it could be a recommendation that when the 5 local area offices are up and running that each of them go out to their local area and find out what people actually want.
- You will find in each area that there has already been a survey and they might have that information already there.
- If they have already done work, bring in the good work and the good practice that has already been done – there is no point in reinventing the wheel.
- The PCC and their representatives should be represented on Neighbourhood Partnership Boards. They should get the pulse of what's happening in the local community.
- This is the last meeting that I will be attending. What I'm going to do is collate experiences. Build up a database of people's experiences and forward them to Stormont. My time is worth more especially to attend meetings.

## **18 FEEDBACK ENNISKILLEN – 18 NOVEMBER 2008**

### **PR/Access to Information**

- Any booklets that the old Council produced were full of language that you couldn't understand and it wasn't in plain English and they didn't include any information that we wanted to know.

### **Complaints Procedure**

- A lot of things are nice on paper but when you look at it at a practical level it doesn't work. My son was in car accident and he went through all the hospitals and rehab. There were so many things that looked lovely on paper, but you dare not go and complain because they have such rigid structures. You couldn't voice your opinions.
- There is no structure there to complain. If a Council is really working to help people they must make sure that it is not such a daunting thing. It's not against a certain person, it's that certain things don't suit certain people. It should not be taken personally.

### **Structures/Functions**

- The Council can represent the interest of the public by talking to the public in plain language.
- The first thing is who do we ask? The starting point could be that they go to every county and see the registered groups and ask for a representative. It has to be all inclusive and that is not happening at the moment.
- If you want to put a message across to someone, or find out what people want to say about a new service or on anything that you are going to do. You ask the people.

## **PR/Access to Information**

- They will have to advertise who they are because I didn't know they existed or what they stand for.
- The best way to advertise is in the local papers or GP surgeries.
- Regarding advertising in GP surgeries they go as far as the counter and that is as far as the leaflet or poster gets.
- In GP's surgeries there are too much and too many leaflets and posters. There should be fewer leaflets and posters.
- GP's surgeries are not a good place to advertise.
- There should be a website. Some people with mental health problems don't want to go to meetings but their voice should still be heard so there must be a choice of methods.

## **Community Care**

- When you are sent home after surgery there's no support there. How could that issue be solved?
- When you get out of hospital they don't ask "what are your needs"? They just say this is the programme. You either follow it or go out of the NHS and go private.
- You should be asked if you need someone to visit you and not the other way around.
- Before you leave hospital you should have a social worker, for example, someone there to help you to ensure everything is in place.
- To ensure you get help a phone number should be provided as back up.

## **Surveys**

- People don't look at comment cards. They put them in the bin. If a group was set up to look at them it would be a good idea.

## **Complaints Procedure**

- It's a good idea to have a group from each hospital that could meet once a month and any complaints are brought to that meeting.
- All these evaluations are being done by the people who are providing the service and that is not fair. It should be someone neutral.
- My experience of the complaints procedure is that there was no communication in the ward we were on. I wrote and did complain to the nurses on the ward and they knew what went on wasn't right but I didn't hear anything after it.
- Is this PCC supposed to be the Watchdog? How far will their remit go? Will they bring the complaint for you or will they just help you write the letter or inform you what they think is the next step but they will not take that next step with you.
- You would need a solicitor onboard as well.
- We don't want to be involved in anything that hasn't any weight.
- I made a complaint about the ward. They gave me one of those cards, I thought it was a good idea. I filled it out and sent it on but I didn't hear anymore after that.
- Another issue that went on at the Erne Hospital. I complained to the nurses and they told the sister and the next day the sister was on the phone to me and asked me what I was complaining about. I wrote a long letter and never heard anything further.

- If there is going to be complaints procedure there has to be a timeframe.
- There has to be a policy that when the complaint is received there has to be a timeframe when they will get back to you.
- When you send in your complaint within 28 days you should have something back. The system has to have a start, middle and end.
- When we had changes in the Tyrone and Fermanagh Hospital it was as if the staff weren't being trained on these changes. Around the top table it is happening but it is not happening on the ground. The staff need to be trained. It should be all about change and the staff should feel good about it as well.
- It's a win, win situation if things get resolved.
- When my son was in the Erne Hospital he was caged in one room and he fell twice from the bed. The staff hadn't a clue how to deal with multiple injuries. They put him in the surgical department, he had head injuries and multiple injuries. The system was so rigid – it was “this is the hospital and we know best”. He was not allowed to watch television etc and he was just out of a coma. We had such a terrifying time and no one even dared to tell us we could complain.

## **Appointments**

- Regarding promoting the PCC or involving the public there needs to be some incentive. The payment should be the same, no difference made between professional and lay people.
- To be valued as a common person representing the community is very important.

## **PR/Access to Information**

- There must be information on where the PCC are, their opening times, are they accessible, is there a telephone number or free phone number.
- As well as a free phone number they should have another option like email and easy, understandable forms.

## **Community Care**

- My hospital appointment next week is at six o'clock and I can't get an ambulance for that time and can't get another appointment time.
- Staff awareness is very important. We have been to so many hospital appointments. Some appointments were at the Royal Hospital at nine o'clock in the morning. They know we are based in Enniskillen so we had to ring up and say we can't make it for that time.
- There are issues around the ambulance service. I would not drive to Belfast. The first time my daughter wanted an ambulance as she was coming out of hospital, I arranged with the hospital for the ambulance to come to Enniskillen however it left her behind so she had to get a taxi which cost her £60.
- Another time we had to get the ambulance at eight o'clock we got a phone call to say there was no ambulance going that day. We had to cancel the hospital appointment and doctors don't like cancelled appointments.
- Older people and people with disabilities cannot drive to Belfast so they need to have some sort of transport system in place. If they had a group of people from Enniskillen going to a Belfast hospital, those people could get the rural bus and it wouldn't cost that much. They need a good reliable transport service.

- If you have to go to Belfast or Derry, they should provide a service because to get the bus from here to Derry would take you all day.

### **Location**

- The office should be based in community buildings which should be accessible.
- They should be mobile, a day in Derry, a day in Derrygonnelly etc. You don't need an office these days.
- It could be in different accessible centres once per month.

### **Training**

- Staff training is very important. Businesses carry out staff training why shouldn't the PCC.

### **Inpatient Hospitals**

- Hospitals don't have enough auxiliaries in the wards. Nurses have to do everything. If you need changed or need a drink nurses have no time to do these things. Auxiliaries are so important.
- Men and women in the same wards that should not happen.
- If I had gynaecological problems I would rather talk to a female doctor than a male.
- In one instance after my car accident a social worker watched me shower. She was a female and I am a young man, I was 19. That should not happen.

## **Appointments**

- Need to ensure that the lay representative and voluntary representatives are made up of the Section 75 categories. We need representation on the Board.
- Councillors on the Board could have a conflict of interest.
- The PCC should be made up of people representing different disabilities and ethnic minorities as well.
- I think you need a Councillor there as well.

## **PR/Access to Information**

- I hope they don't spend a lot of money putting out booklets. Advertise a few weeks in the local papers in plain English, that's all people need. Posters in the library too.
- I think it's better to put money into training instead of fancy booklets.

## **Appointments**

- Regarding the criteria to get on the Council – appointments should be made on merit.
- If you have a disability you get waffle sent back to you saying you don't meet the criteria.

## **Structures/Functions**

- The PCC budget should not be decided before decisions are made.
- If changes are implemented we could have inspectors to ensure things are carried out. There should be an inspection body in place.

## **19 FEEDBACK DUNGANNON – 19 NOVEMBER 2008**

### **PR/Access to Information**

- If the Council is being set up as a blank sheet they should use the local press to say that they are there. They should use television as well. They should use this as a good opportunity.
- The PCC should come out and speak on a regular basis to people. They should carry out a good campaign
- In doctor's surgeries there is a computerised information system and television to tell you what is going on. The PCC could use these to advertise.
- Sometimes in doctor's surgeries you are not drawn to what is pinned on the wall but most people will look at a television screen.
- Not everybody has access to a computer.
- Regarding leaflets – blue is different from the rest which are grey and pink. You want a colour that is going to stand out.
- There is too much information on surgery walls and some people's eyesight is not always good.

### **Location**

- Regarding location – if it was based in a hospital it would be difficult to go and complain about the hospital when they are based there. The PCC must move somewhere else.
- It's very hard to get parked in the hospitals around here.

## **PR/Access to Information**

- You have to get as close to ground level as possible. Usually a lot of organisations communicate from the top down when in fact they should be starting at ground level from the outset. Anyone that is aware of this Council - that is fine but for those unaware are they pushing it or are they just sitting on the information they have? That appears to be the situation that I have found – and have personal experience of it.
- To get in at ground level in the surgeries and post offices etc, anywhere where you can get information to where the clients are actually sitting – is to start at the bottom and come up.
- You can spend an awful lot of money on advertising on television and newspapers. I'm involved with diabetes UK. We have tried everything regarding papers etc. I put in an editorial every month about meetings etc and you would be surprised how many people don't know there is a branch.
- What we find most effective is the local paper.

## **Structures/Functions**

- This notion about what they do on the ground is more important, feeding up from the ground and they need good systems in place.

## **PR/Access to Information**

- I have a serious health problem and couldn't find anyone to help me and I ended up in serious difficulty because of that. The professionals need to know that when you have a problem where the contact person is so they signpost you to the proper person.

## Complaints Procedure

- When you ring in to complain you go from pillar to pillar.
- I was never sick or had an antibiotic in my life. When someone like me needs to see a doctor – they thought I had died because I had never been - I had a twin brother killed in an accident and they dumped my records with his.
- As a result I never got treatment for months. I signed myself into the hospital. By going to Accident and Emergency and I was there for 3 ½ months. That was eight months after trying to get help myself.
- I was under the impression that because the health service was under a lot of pressure that was causing the problem. However a lot of the problems are caused by bad management.
- This is why I am annoyed about the local system – I was finally contacted by Craigavon hospital. I went to my GP in Jan 2004 and I was contacted by Craigavon hospital to say I was now at the top of their list and that was November 2005, almost 2 years later.
- Nobody came to see me or to dress my wounds except the nurse. I was out of hospital 2 months and I never saw my local GP. My daughter then wrote a sharp letter to complain at Christmas and I got out of hospital in October and I never saw a GP even though the hospital had told him I was out. So when my daughter wrote the letter I saw the GP the next morning at 9.30am and he apologised.
- The aftercare is very bad. It's not in one particular area it seems to be all over.

## **Training**

- Really we are talking about training for staff, GP's should be trained and the PCC should be there as well.

## **Access to Services**

- Some of the managers in the health service are on £200,000 a year. There's something wrong there. We need more nurses and doctors and more beds.
- In the health service, in their management committees they are now bringing in financial advisors and paying them massive salaries.
- They are paying far too much to management and they should be paying people on the ground that needs it. That money could be going towards cutting waiting lists.

## **Structures/Functions**

- I would be very concerned about Councils. Why should people come in and sit on Council if your recommendations are going to be ignored.

## **Complaints Procedure**

- If you're saying that you don't know what happens information when it is sent in, what different levels or departments it has to go to. I think if your letter was acknowledged by everyone in the chain then you would soon have the person that stopped it going further because you have a paper trail.

## **Community Care**

- The GP should be aware if you need care. I have four daughters but there's none of them at home. So officially I don't have any care.

- If somebody is in hospital they should take into consideration there's no aftercare. If the nurse comes to the house you may not be able to get out of bed to answer the door.
- It's reassuring, mentally, to know that someone is coming out to see you if you do get into difficulties, rather than the panic of coming home and thinking no one is coming out to see you. If you come home and someone gives you the details of who to contact, who you can avail of. You feel much more confident when you know you have the back up of the nurses even if you never have to call them out.

### **Appointments**

- Would it be a waste of time to think about applying?
- You need people who are up to date on computers, emailing. I think quite a few should be young people, but a fair mixture.
- Regarding payment – people with disabilities could lose their benefit or could they be regarded as expenses for travelling to and from meetings?
- I wouldn't be able to sit on the Board because I'm working.
- You have to know where to look for public notices. Some may not pay as high to enable people on benefits to apply.
- Does travelling expenses not come under an allowance or is it separate and not classed as income?
- Under the DDO – they have to encourage people with disabilities to participate in public life – how are they going to encourage them to participate because of the benefit trap. We need to look at that.

## 20 RECOMMENDATIONS

### Appointments

Disabled people are under represented in public life positions as a result of barriers, whether real or perceived, such as advertising of public life positions and/or the recruitment/selection process. For example, essential and desirable criteria can rule out disabled people at the beginning of the process as well as lack of confidence in disabled people caused by negative societal attitude.

Whilst Disability Action is aware that the PCC do not have responsibility for public life positions it does not mean that it has no responsibility in this area as the DDO 2006 duty is to “encourage” not appoint therefore Disability Action requests the PCC to bring the relevant recommendations to the appropriate government department/unit.

In relation to PCC appointments, participants have made the following recommendations:-

- Staff and Board members involved the recruitment/selection process must receive Disability Awareness Training and equality legislation training.
- Equal weighting given to experience as some applicants may not have the qualifications sought directly as a consequence of his/her educational background.
- Capacity Building programme for **all** new recruits.
- PR exercise to encourage people to get involved.
- Time commitment explained from outset in regard to meetings and possible working groups.
- Length of service on Board must include opportunity for a second term contract to ensure continuity of expertise.

- Traditional methods of filling in application forms must be maintained as well as online applications.
- PCC Board must be an equal partnership of professional and lay people.
- The financial complications for people on benefits in regard to fees must be addressed.

In relation to PCC appointments, Disability Action has made the following recommendations:-

- A review of the recruitment/selection process from advertising, job description, application form through to interview.
- Board must be representative of Section 75 groups.
- All recruitment/selection materials must be offered in a range of alternative formats.

### **PR/Access to Information**

The availability, accessibility, accuracy and quality of information provided are vital factors in removing information barriers. It is consequently imperative that the PCC ensure that access to information mechanisms are put in place to lessen the disadvantage experienced by disabled people as a direct result of inaccessible information.

In relation to the access to information, participants have made the following recommendations:-

- PR exercise to inform people with disabilities that PCC exists.
- All information made available in plain language, alternative formats and easy read.
- Produce booklet on new PCC including its role and remit.

- Ensure promotional materials and logo colours are appropriate for people with visual impairments.
- Consult with disabled people on best way to advertise and also other ways to consult.
- Remuneration for people with disabilities who attend meetings or consultations.
- Free phone number that includes textphone or mobile number.
- Produce accessible leaflets and contact numbers – no talking machines.

In relation to the access to information, Disability Action has made the following recommendations:-

- Review information materials and form filling requirements to remove the complexity and the insurmountable barriers faced by disabled people.
- Training of staff on the practical requirements of meeting accessible information supply and demand. Especially, information must be provided for people with a new diagnosis and on discharge.
- A separate budget for the provision of PR and alternative formats.
- Disability Action recommends that the level of accessibility of the PCC website must meet current European Standards.
- Board members and staff must hold regular meetings with disabled people.
- Research PR methods through consultation for most cost effective marketing methods. Rural versus urban divide.

## Complaints Procedure

Participants were not generally aware of the health service complaints system and they were confused as to the current HSSC role regarding complaints. Disability Action recommends that the new PCC consult with service users with disabilities to determine an effective system that delivers a user friendly complaints procedure.

In relation to the complaints procedure, participants have made the following recommendations:-

- Public awareness campaign on complaints procedure which must be designed in partnership with service users.
- Production of a plain language step by step guide on how to bring a complaint. Both booklet and internet method.
- The complaints procedure must carry out commitments made in leaflets, for example, a 28 day response must be adhered to.
- Complaints procedure system must be delivered independently and accomplished within a given timeframe.
- Ongoing training for complaints procedure staff.
- Consistent approach to complaints procedure across all 5 locations
- Independent evaluation of complaints procedure.

In relation to the complaints procedure, Disability Action has made the following recommendations:-

- PCC should review all H&SC complaints procedure in conjunction with people with disabilities.
- Disability Awareness Training for staff and board members.

## **Location**

- Disability Action recommends that all new and existing buildings should be designed to exceed the minimum standards of the building regulations in order to future proof the PCC services and better embrace the spirit of the Disability Discrimination Act 1995. Accessibility should be addressed in the widest context – that is taking account of the location of the site, the access across a site as well as access into and throughout and egress from any building on the site. Disability Action highly recommends that specialist advice is sought from an expert in accessibility including local disability sector representatives. The PCC would need to consider, for each of the five offices, compliance issues under the Disability Discrimination Act 1995.

In relation to location participants have made the following recommendations:-

- Move PCC offices from hospital setting.
- Consult with disabled people on central office and local office location eg use of community buildings and/or a mobile for outreach programme for rural areas.

In relation to location Disability Action has made the following recommendation:-

- All locations must be fully accessible to people with disabilities. Disability Action recommends access audits for all five locations.

## **PCC Structure/Functions**

Disability Action believes all functions and policies that relate to the new PCC must be assessed to ensure equality of opportunity and positive images towards disabled people. This must include training, provision of support services, mainstreaming of equality policies, employment of disabled people and portrayal of positive images.

Disability Action recommends an action plan to establish outcome driven measures which are specific, measurable, achievable, realistic and time-bound (SMART). This will enable the action plans to be achieved rather than create unachievable aspirational plans although commendable rarely achieve real change.

In relation to PCC structure/functions participants have made the following recommendations:-

- Set out a realistic timeframe for implementation.
- Develop an action plan.
- Capacity Building for Board members especially lay members to ensure active participation and partnerships.
- Five local offices must consult with local people.
- Consistency of role and responsibilities between five offices.
- Disability Awareness Training for staff and Boards.
- Bring HSSC a good practice to new PCC.
- Board and staff representation on other pertinent groups, eg neighbourhood partnerships.
- Establish a clear relationship with other watchdogs eg RQIA.
- Adopt a plain language policy.
- Decide on an inspection role – secret shoppers.

In relation to PCC structure/functions Disability Action has made the following recommendations:-

- Consult and prioritise issues, in conjunction with disabled people and act on responses.

- Engage with local groups and organisations to set up local fora.
- Set up two way communication for feedback to keep public informed.
- Clear outline of role and responsibilities eg closures of residential homes in regard to DHSSPS policy.
- Clear mechanism to feed from grass roots to top level and vice versa.
- EU standard and easy to use and interactive website.
- Develop appropriate monitoring and evaluation systems.

### **Access to Services**

Disability Action would advise the PCC that access to services is about more than the physical access to the built environment. The PCC must be concerned with the broader issue of access, in relation, to the service in question ie alternative information, geographical location, time of day, travel distance, car-parking etc.

Additionally, the ability to access the necessary services directly impacts on the quality of life of disabled people and too often there are many barriers which can obstruct independent participation in accessing services. This is evident from the many comments on in-hospital and community care detailed in this document.

Disability Action believes that a holistic approach to a disabled person's individual need is absent when accessing services especially when it requires two or more agencies or units within an organisation attending to the issue of concern. This requires multiple attempts to overcome barriers at different points of service delivery.

The comments detailed in this report highlight these concerns. Disability Action believes that much of this feedback could provide the new PCC with a list of issues for future work.

## **Training**

Other peoples' attitudes are one of the biggest barriers disabled people face in all aspects of life. Service provides place an over emphasis on the medical model interpretation of disability which focuses on the person's impairment rather than the social model which focuses on how society structures its institutions and the environment. Disability Action recommends ongoing high quality training, delivered by specialists, to demystify the perceptions and stereotyping that disables people face.

Participants recommend that all PCC staff and Board members must receive the following training:-

- Disability Awareness Training
- Equality legislation – DDA 1995, DDO 2006, Section 75 and Anti-discrimination legislation
- Capacity Building training

## **Research**

Disability Action recommends the participation of people with disabilities in the development and design of any PCC survey/research.

## **Local Fora**

The PCC should look to the provision of support mechanisms to enable meaningful engagement and to the leadership it can offer others in terms of good practice to influence change within the health service.

Disability Action recommends the PCC to consult further with local individuals and representative organisations regarding establishing local fora to determine their terms of reference and communication mechanisms between local and central office.

Additionally, a scoping exercise should be completed to determine the number of user service groups already established within the five Trusts to gain a clear understanding of all the different groups and their roles and responsibilities.

## **21 CONCLUSION**

The Health and Social Services Council and Disability Action would like to thank all those who contributed to the public consultation process. Disability Action recommends that copies of this report be sent to all participants and will be made available on request in Braille, Large Print, Audio Cassette, Computer Disk etc.