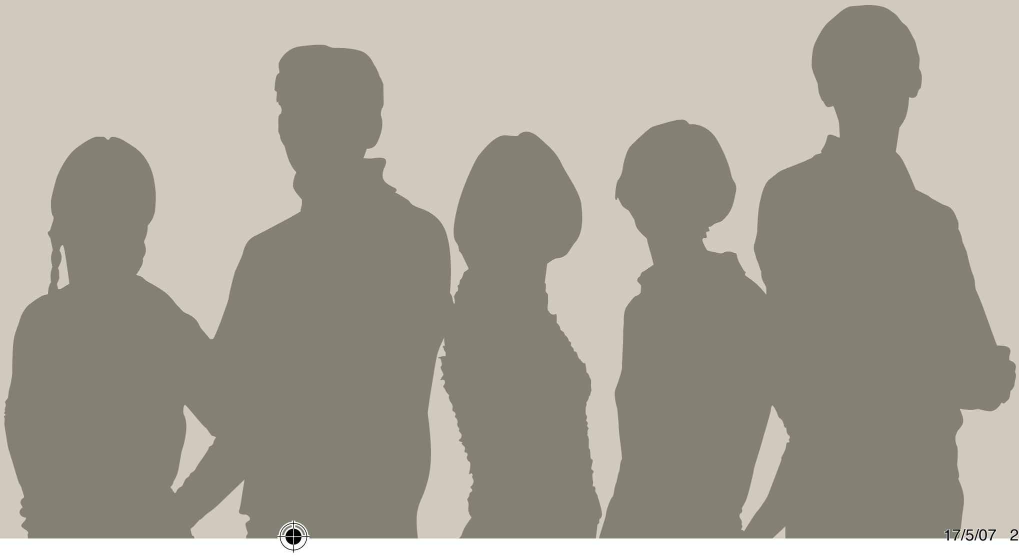
Participation and the Practice of Rights Project

Making & Measuring Change
A Human Rights Based Approach to Health

Conference Report May 2007



PPR
Participation
and the Practice of
Rights Project

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Foreword, Paul Hunt, - UN Special Rapporteur on the Right to the highest attainable standard of Health

I first worked with the PPR Project in December 2002 when visiting Belfast as a member of the United Nations Committee on Economic and Social Rights. We discussed the work of the Committee and the importance of non-governmental organisations and community groups feeding into UN human rights processes. We also looked at the idea of measuring, at the local level, the progressive realisation of economic and social rights.

Because economic and social rights are subject to progressive realisation, what is required of the authorities varies from one year to the next. Some States tend to abuse progressive realisation: they try to use it as a way of escaping from their human rights responsibilities. One way of stopping progressive realisation becoming an escape hatch is to devise ways of measuring it. And one way of measuring progressive realisation is by using indicators and benchmarks.

By supporting communities to set human rights indicators and benchmarks that measure whether their economic and social rights are being realised on the ground, the PPR project is applying two fundamental features of the human rights-based approach to social change.

First, the project is identifying indicators and benchmarks that measure and monitor progressive realisation. Second, it is doing so by way of a participatory process: groups affected by the issues are setting their own human rights indicators.
This participatory element draws upon the work of academics, human rights activists, lawyers, community development workers, social housing residents and health service users.

In short, the PPR project is imaginative and ground breaking. This conference marks the start of the project's detailed work on indicators. The project is of great interest to many - in the island of Ireland and beyond - who are committed to economic and social rights. We all look forward to learning from the project's progress.

Paul Hunt

May 2007

Opening Welcome & Introduction - Inez McCormack, Project Chair

You all are very welcome. Many of you have been on this journey with those of us who've been involved in this project for some time. We had our first discussion in the Carrickdale Hotel nearly five years ago when a number of groups came together from communities, from Human Rights NGOs, from Trade Unions and from academia to try and work out how we could apply a rights based approach to the issues of relationships between the powerful and the powerless.

There was a context then and there's a context now of the growing gap, North and South, between the rich and the poor. That gap is evidenced in relationships between those who feel powerless and excluded and those who exercise decision making in the allocation of public resources and the delivery of public services.

And, quite often that relationship can be characterised by antagonism, bewilderment, hurt and humiliation. The question is how to change those relationships. And, fundamentally the definition of any rights based approach is the ability of those who are affected by the absence of right which is, in fact, the presence of humiliation – to participate in the decisions which affect their lives.

The collision between those who are affected by exclusion and those who deliver resources often happens in way which breeds a great deal of negativity – to put it politely – on both sides. How do we change the basis of those relationships? And how do we ensure that change which occurs can be measured in terms of the dignity and respect accorded to the people who need the change? That's the rhetoric and making that a reality is the purpose of the project.

A lot of you have been with us on the journey and you are very welcome here today. There are many different strands to the project and there are many different kinds of sectors and groups in the room.

I look around the room and I see some of the policy makers and decision makers involved in the delivery of care in the room – and that's extremely welcome – because it is not a question of good or bad or right or wrong in terms of people who make policy.

Quite often people who make policy and deliver policy live in the absence of any relationship with those who are actually experiencing the effects of the policy at the hard end. And what we want to do is create those relationships, but the relationships have to be created on a basis of equals.

There are many strands, as I've said, there's North/South, human rights, academia, communities. But, one of the important purposes of this project is to recognise that we are trying to learn lessons in the way that we do our business that can be replicable elsewhere.

We took a decision, about two years ago that we would try and see how the project would have concrete application in two communities - in some areas of North Dublin and some areas of North Belfast.

Both jurisdictions represent communities who live at the hard end. Within those communities there are people who are vulnerable and excluded, and, quite often, treated as though it is unnecessary for them to be consulted or involved in what effects their lives.

Making rights real in those people's lives is, to me, the test of a human rights based approach, because frankly, if you can make that relationship work, everything else becomes possible.

The Project is now working in North Belfast and North Dublin. We've got funding and resources for three years. We have got policy and development staff working with the communities. But, the test, as somebody said to me, is not so much what we can achieve in North Belfast or North Dublin – although that is extremely important because in a sense we're as good as how far we actually enable people to feel that they get a result – but also, if communities that do not have a million pounds worth of resources over three years can use the human rights based approach model and make it work.

If we cannot have ways of learning lessons about how we're doing our business, in what way we're doing our business, that are useful and replicable to other communities and other groups, then, frankly, it's not worth doing because it will disappear like a snow off a ditch after three years, both in North Dublin, North Belfast and elsewhere.

The whole core of this is how do we make the change in power relationships sustainable by the transfer of skills and resources to the people who actually need the change. And it's not that they lack expertise – they are the experts in their lives. What they lack is the sense of context which requires that expertise to be treated with respect. Then they can feel they are actually part of getting the answers, and enabling the decision makers to change their ways of doing business.

Another of the many strands of the project which is core to what we're doing is the link between the global and the local. Right from the beginning we have put the context of a rights based approach in an international setting. There are rights to health, rights to education, rights to housing which a majority of governments have signed up to. Certainly, the British and Irish Governments have signed up to.

I'm quoting a woman from North Dublin when she described them as "the best kept secrets in the world". She had no knowledge that she was a citizen of a country which had signed up to rights to health, right to education, right to housing, in which she was actually entitled and enabled to participate about what that meant in her life.

How do we make the connection between these standards and those who are working on those standards at the international level, and the expertise of the people who are coming from the communities?

Another part of this project is we're not just doing a project in three years, we produce a report and we disseminate it to everybody. The whole way we've done our business is every step along the way that we've had broader discussions on enabling people to feel that they can intervene and engage. Because this isn't a project belonging to us. Any lessons learnt, any clues, any information are open to everybody to take away and use. And everybody's input is welcomed in terms of how we shape the next steps.

We have with us Paul Hunt who's the UN Special Rapporteur on the right to health. Paul came for a discussion a couple of years ago and he really helped with the local communities to break this log jam of people feeling – 'right to health, 'right to education', those words sound great, but they mean nothing to us.

mean on the ground'. He helped us break the log jam in terms of how we could move forward, in terms of the project then. And we are now moving into the next step of the project as you will hear, in terms of the communities in North Belfast having identified issues in which they believe lessons can be learned that are useful to groups that are vulnerable in their communities. They will be speaking about that today.

The question is to get an engagement between the information and evidence that is coming from the ground, and from the work that Paul is doing – and as we move forward then, how do we make those two engage to set indicators that policy makers and those who need the change respond to?

How do we measure the delivery of care, the delivery of health, the delivery of any of the economic/social rights in a way that the indicators of change measure the involvement of the people who are affected?

And, in a sense the bottom line is you start off what changes the initial humiliation into a language and behaviour of respect.

Another point is - how do you sustain the result? Power will respond to pressure to make a change but when the pressure goes off, we can go back to old habits. Especially when it's people who are the most excluded or the most marginalised.

And in a sense that's the core of this project, that unless we actually enable the tools for change to be held, owned and used effectively and successfully by the groups who need that change, then power will simply respond in its old habits once the pressure goes off. And that's a hard lesson to learn but it's the truth. We need ways of changing that aren't just about confrontation but are about actually creating effective relationships between the excluded and those who are decision makers.

So that's where we are today. So you're all extremely welcome and I would like now to introduce the representatives of the communities from North Belfast and North Dublin who are going to give you some identification of the issues.

Could I just say to you that what you are hearing from the representatives are the particulars of their issues. But in your briefing pack there is actually a note on the context of those issues, in terms of statistics and information, in relation to North Dublin and North Belfast. But we didn't think you'd find if very helpful for us to present you with statistical information as part of this information. This is about discussion and how we move it forward. So, you're all very welcome. Let's have a productive day.

The Right to Health - The Reality in Our Communities

Suicide & Self Harm in North Belfast

Stephanie Green, PPR Project
(For Gerard McCartan, PIPS)

I'm Stephanie Green and the local development worker in North Belfast for the PPR project. I'm standing in today for Gerard McCartan from PIPS (Public Initiative for the Prevention of Suicide). Unfortunately, Gerard cannot be with us this morning.

Gerard and Carol McCartan lost their son, Danny, two years ago – tragically – to suicide. When I met with Gerard and with Carol, their story was extremely moving. I actually felt physically shaken after hearing what they had been through - the lack of respect they experienced through the various health and social services and others over a number of years. In fact, since Danny left primary school.

Danny took his own life at the age of 18. Since he left primary school the McCartans had a lot of problems dealing with various health and social services. Because Danny had some mental health problems.

When Danny took his own life, Sean Woodward, who was the Northern Ireland Minister for Health at the time, offered to do a review into Danny's case because there were so many issues coming up through it.

That review began in March 2006 and the McCartans were told that it would only take three months. It's still ongoing. And, in fact, they were told that they would be kept informed about how the review was going and yet, they've heard no information.

It actually took Gerard to speak to Paul Goggins, the new Minister for Health who replaced Sean Woodward, at an event to say, 'Look, Paul, we haven't received any information. This isn't very fair given what we've been through.'

And I think now they have received some information but, again, it shows that how people are often treated with that lack of respect and dignity that is due to them given the circumstances that they have been through.

It's also worth noting that people who have lost somebody through suicide are often at higher risk at taking their own lives themselves. So, it's even more important that they are treated with the respect and dignity which is due to them.

Another thing which struck me when I was speaking to Gerard and Carol was that they had been encouraged by the health trust to make a complaint about the services that they had or had not received.

Unfortunately, I think they were told in such a way which left them with more confusion than when they started. They were told that there were complaints forms that they should fill in.

They tried to track down these complaints forms but there were no complaints forms and they only found out by going to the Ombudsman, going to different places. And, I think it was a journalist for the BBC who finally told them that, in fact, you have to write a letter.

So, this family who had already been traumatised were advised to do something and yet didn't receive the due support which you would imagine a family in those circumstances would receive.

To add insult to injury, the Trusts, - the complaint was actually taken against five Trusts - did not respond within the time guidelines that they were supposed to. One of the Trusts took 90 days to reply to the initial letter when their guidelines say 20. One of the other trusts took 25 days.

Some of the other points Gerard and Carol would have liked to have made is that they realise that they're in it for the long haul, in terms of campaigning, that this is just a start. They have helped set up PIPS -which is the group Gerard would have been representing here today – which was set up to help families bereave through suicide. But, they also said they feel as if they haven't had time to grieve.

Gerard is, in fact, just back from a trip to America and one of the things that he noticed there was that medication which could cause suicidal tendencies in young people is labelled with big letters on the sides of boxes. It's very obvious and very clear. Whereas here very often that sort of information is either in small print on a leaflet in the box of tablets or sometimes a leaflet isn't even in the box of tablets.

Gerard also mentioned that it takes six-months to get an appointment to get specialised help for those who are feeling suicidal and obviously, for those people involved in that kind of emergency situation, six-months is far too long.

One of the other things in terms of their own son that they faced was that when Danny turned 18 he actually lost his social worker on Christmas Eve – due to when his birthday fell. That social worker was somebody Danny trusted and believed in and it wasn't a lot of time after that that Danny actually took his own life. Gerard would like us to highlight that there's a gap in the service there.

Also there was no consideration of what the person suffering the problems actually want. Danny said he wanted to go to group therapy but was told he had to go to one-to-one sessions first.

Gerard, since then, has been heavily involved in campaigning to get extra services for people who are either self-harming or suicidal.
One of the things that they have done is set up a youth facility with some others because they felt there was very little for young people, in terms of provision for preventative work around suicide. Gerard was told - and this is a quote directly from Gerard - 'you're on your own'. Gerard went ahead and set up the facility anyway and it's now very successful.

I hope those are the main points Gerard would have wished to put across to you. Thank you very much.

Eileen Weir, RAYS

I'm here today just to give you a bit of background on some of the work that's been happening in the communities. And for people from Dublin who maybe don't know the whole story around the struggle for people to get treated equally within working-class areas of North and West Belfast.

About a year, maybe nearly two years ago, the families in West Belfast and North Belfast got together and lobbied Ministers. They stood outside buildings with placards and they were seen and the TV cameras caught it.

From that it was decided that we should set up a task force spearheaded by the families of people who had lost loved ones through suicide.

So they spearheaded this campaign and sat on a task force for over a year. And, eventually, we got the Protect Life Suicide Strategy for Northern Ireland. And if everything was implemented that was in the Protect Life Strategy we would probably be able to save lives.

And there are things within that document that haven't been put in place. So they have set up a family forum and there's a regional family forum who sit on the Protect Life implementation body.

There are six family members on the implementation body from the whole of Northern Ireland. There are supposed to be six community reps from the whole of Northern Ireland which it hasn't been decided who is going onto it.

There are spaces within the body, there are empty chairs of people who said they were doing things but when it came to it they're missing.

First port of call for families who are stressed is the doctors. We're still getting Danny's story within our doctors' surgeries. We're still getting turned away at A&E. We still have no beds for anybody under the age of 18. We don't have the joined up working that's in every page and every sentence of the Protect Life document.

So we are going in a circle. We are on a round-about and we can't get off this round-about. And, if everything in that document was implemented we would probably be able to save more lives.

Over North and West Belfast, and I have to say this because my friends down there from West Belfast will shout at me if I don't, from the Greater Shankill, are all together in this trying to fight this campaign for equality and health and to be treated equally within our health services.

We're working very much in conjunction with North and West Trust in this issue. And there are some good people there with us – working along with us – and campaigning along with us. But, we can only take it so far and then we're not backed when it gets to the level where the decisions have to be made.

This is a document that we don't want to be sitting on the shelf. The Greater Shankill was lucky enough to get money from Renewing Communities who recognised the need and set up a project called, RAYS. We have two support workers and an administrator, and although we haven't even advertised our services yet, we are working constantly.

I actually was out to a family the other day. The woman was in distress. Her young lad, three years ago when he was 23 took an overdose. He was put into a unit which probably wasn't suitable for him. Then they let him out and said he was okay – even though he was hearing voices in his head telling him he wasn't okay and that people were coming after him.

In October 2006, he took another overdose. When he went back to the doctor, they said there was nothing wrong with him. The young lad could still hear the voices in his head saying that people were running after him. His mother pleaded with the doctors to keep him in hospital. But, because he was over the age of eighteen they wouldn't take the parents opinion into account.

They talk to the patient who has a mental illness, who will say anything to get out of hospital because the only thing they want to do is take their lives. So, the patient can actually talk very, very sensibly to say that they're alright, nothing's going wrong, I'm okay to get home. The mother is telling the doctors that he's not okay, he wants to get out because the only thing in his mind is to take his life.

They let him out onto the street. Unfortunately, that young lad thought the only place that he was safe was in the attic of his house. He went up into the roof space of his house. He stayed in his attic – the only thing he took up with him was glasses of water and he felt safe. Every time anyone knocked at the door he had knives with him, he had batons with him, to stop the people in his head from coming to get him.

His family couldn't get the young lad out of the attic. So they decided if he feels safe there, they would let him stay there and watch him. Unfortunately, he took the slates off the roof, got up onto the roof and jumped off.

This is a young lad that was discharged from the hospital a week before. He's now just out of intensive care and he's in a coma in the Mater Hospital lying in his bed. His family are distracted.

A lot of these families who have been bereaved through suicide have been carers for many years. They are on watch 24/7 before they've lost their loved one. And even when they do lose their loved one, they are watching the rest of the family 24/7. They're watching their other children. They're going in and out of their rooms seeing if they're breathing.

Surely they should be getting their equal rights to health care and support. These families are not workers – they're not being paid. And they're running this campaign for proper services mainly on their own with the help of some good community organisations.

All we are asking is when we keep them safe and we get them to the doctor's surgery, the doctor can guarantee their safety until they get them somewhere.

We can only take them so far. We can only keep them alive until we get to the stage where we have to refer them on to another agency within the mental health service.

We need the doctor's surgeries. They're getting paid – we're paying our taxes. We are entitled to a service. We are entitled to the same service that they would get in a middle-class area of Belfast.

We owe it to the people out in that community who are self-harming. They're not attention seeking. A good kick up the backside will not do it. And we want to get away from that attitude of go and get yourself a job or a good kick up the backside.

When I went to the interview for this job with RAYS they asked me, 'What do you think is causing suicides in the Greater Shankill?' I could have spent my whole interview telling them. You have paramilitaries, you have drink, you have drugs, you have debt, you have lack of housing, the list of what could be causing it is unbelievable. But, nobody has the answers and until we get the answers everybody should be playing their part and not leaving it up to families and up to the communities.

Carol and Gerard McCartan have campaigned right from the word go to try and get this service right by putting complaints into five health trusts which were involved in their issue.

One of the reasons they did this was to get justice for Danny. But it was also to make sure that this didn't happen to any other families.

I can tell you this is happening daily to a lot of families out there. And we're trying to show them that they don't have to accept this. Unfortunately, people think this is acceptable. We need to raise the awareness that this is not acceptable.

I'd like to thank you for listening to me.
Emily Reaper, UISCE

- Health Care in North Inner City Dublin

Emily Reaper, UISCE

Hello. My name's Emily Reaper. I'm from an organisation in the North Inner City of Dublin called UISCE. It's an acronym for Union for Improved Services, Communication and Education. The group is run by ex- and current drug users and we represent drug users at policy level because there was a lot of bad things happening to drug users, and as drug users we knew what was happening and we thought we would like to represent them.

When the PPR asked us to get involved through Tom Redmond in the North Inner City, we were delighted. And the whole area of rights and the language that's been used we found has been very empowering. We found that we had the right to demand things and we set about having groups and this is the process that occurred.

And we produced a report called, 'We're People Too' with the help of the Mountjoy Family Practice, Fiona O'Reilly and UISCE and Tom Redmond, from PPR. That report can be accessed through the internet at www.ndc.hrb.ie/attached/2783-Were_people_too.pdf

In August 2005 we got 25 drug users, over a three-day period, eight on average in each group to come and participate in finding out what it was like for them to access primary health care. All the people that we spoke to in the group were on the methadone maintenance programme in a local clinic.

The groups brought up the topics. We didn't suggest anything really. The problem issues that come up for them included access to a medical card. Doctors are the gatekeepers to having a medical card and in order to get one you have to get a doctor to sign a form.

Now, that area we looked at, where doctors didn't particularly like the look of them, the sound of them or the fact that they were drug users, and they were refused on some grounds. They were refused medical cards because they wouldn't sign the form. They said that they were full or used various excuses not to take them on.

And, in doing that, that meant that drug users couldn't access dental treatment, they would have difficulties when they went into hospitals, A&E. They would have to pay money on the spot if you don't have a medical card when you go to A&E – which they wouldn't have the money for. So, it caused various problems.

Other areas identified were hospital treatment. When you went into hospitals there were stickers put on people's charts, red stickers, orange stickers, to identify them as drug users because they were a high-risk case of diseases and so forth. And drug users felt that they were being treated very differently. They were either hurried into a bed, which we'd all like to be hurried into a bed in A&E, or else they were left on chairs for days.

Now, in saying that, the ones that said they were hurried into a bed – they had a problem with that because they weren't being treated like everybody else. That's what they wanted: to be treated like everybody else. But they felt that they were being discriminated against. They felt the attitude of staff – in one particular hospital I have to say, and that's the Mater Hospital in the North Inner City – was just horrendous. And they also said to us, the attitude to the old people in that hospital was also horrendous.

So, the attitude was to people who felt that they hadn't got a voice. And drug users feel because they are criminals – deemed criminals – because they use illegal drugs – that they haven't got as much a right to things as other people. But, they also identified old people as being discriminated against in hospitals as well – in the Mater Hospital.

When we spoke about James' Hospital, which is on the southside of the City who have been dealing longer with the issue of HIV and drug use, the standard of care in that hospital has seems to have risen quite a lot and we commend them for that.

The other issues that were identified were psychiatric care and like the other talkers were talking about, suicide. People were admitted to psychiatric hospitals for suicide attempts. And one person said that she was admitted for attempted suicide, and was let home the next day because she was a drug user.

Seemingly, when you go into a psychiatric hospital in Dublin if you're a drug addict they say they can't deal with your psychiatric problems because you're administering drugs to yourself so they can't see the real problem. Because you have a psychiatric problem the drug specialists say they can't really deal with your drug problem properly because you have a psychiatric problem. So there's nobody really dealing with the two problems. They're enmeshed.

And there seems to be a huge problem within the clinics who treat drug users with this whole area of dual diagnosis. Nobody's taking responsibility for that either – the psychiatric issue that's going on with a lot of drug users.

Another area that was mentioned was the whole area of methadone treatment. In the late 1990's there was a new protocol in Dublin and that was that doctors had to be trained in order to prescribe methadone – that no doctor could prescribe methadone unless they were registered. And they're written on special prescriptions.

Now, in doing this there's a shortage of doctors now who can take on people within the community. In the clinics there can be 3 to 360 people attending in a day. And, if those people are doing well they get farmed out into their own community. And they get treated by doctors in their own community and go to their own community pharmacist.

But, there's a shortage of doctors in the North Inner City. I have numbers here but I'm a bit baffled by all the numbers. But there's a bloody big shortage of doctors within the North Inner City to write methadone prescriptions.

I think they see drug users as just a big ball of trouble. And they're just not willing to take them on. Plus, I don't know if it's the money or not but if you're seeing a drug user you have to see them once a week. Anyone on the medical card, if they come to you once or if they come to you 50 times or don't come to you at all, you still get paid for them once you have them on your medical card list.

UISCE took on a lot of research years ago when we first started and asked drug users what would they like us to represent them on and it was about methadone. The people in the focus groups that we had with PPR – they said that they were on methadone for 20 years. There was no incentive to get off methadone.

They were delighted to be on it but there was no incentive to come off it. And that they were becoming grannies now and their grandchildren were looking at them taking this stuff every day of the week and they didn't want to be doing that. And when they went to their doctors asking them if they could be detoxed the answer was 'no'.

There was a whole range of reasons as to why that was happening but lately we've been challenging the clinics and they've said that they're not saying 'no' to people anymore. And because of the work we do, and I believe there's a whole new fifth pillar being established where they're looking into the whole area of rehabilitation and residential treatment and trying to encourage people to come off methadone because people are staying on it far too long.

Another area that people weren't happy with was pharmacies. My Mum had a pharmacy so I kind of know the ins and outs of it. But some pharmacies handed drug users a contract when they came into it. And just to give you an idea of what these contracts said – it's pathetic.

It said on the contract you may not come into this chemist to buy anything other than your methadone. If you want to buy something else you must leave the chemist and walk in again. So you must come in collect your methadone, leave and walk back in to the chemist again. You cannot bring anybody with you into the pharmacy whilst you are collecting your methadone.

They can stop dispensing your methadone for any reason and you cannot complain about it. If you are caught robbing – then your methadone would be finished. The dispensing of methadone in that chemist would be finished.

You could not have anybody wait outside the pharmacy for you. You cannot bring anybody with you. Even some people who are very ill with HIV and hardly able to walk had to go into the chemist on their own with no family member or anything to collect that.

Now that's just utter discrimination. But this was actually written down on a sheet of paper. And we have these in our office and we showed them to the Irish Pharmaceutical Society and I don't think they really could believe what was written down.

But, it's up to each individual pharmacy to do what they like. There is a recommendation that if they want to do a contract it's a very simple format and the only thing I think that we disagreed with was that no drug user, collecting their methadone was allowed to bring a mobile into the chemist. Like everybody else can bring their mobile but no drug user could bring their mobile.

So, we're fighting against all things like this. The PPR kind of empowers us and the language that's there that we can use when we're backing up this stuff is really empowering and it encourages us to continue fighting for the rights of drug users.

Also, drug users had a problem because when you go to the Mater Hospital there's a big sign in red and it says, 'infectious diseases'. And you must go in here. People who are HIV-positive have to go in here and people in their own community can see them going in and they feel very embarrassed about that.

And, we went to ask the Mater Hospital, myself and the other people who worked on this project, would they mind changing that sign and we were blatantly told, 'no'. And there was no discussion about it.

And when we spoke to this consultant, he told us that his patients in the wards love him. We were sitting there really in disbelief thinking, is he for real because his patients are telling us terrible things about this man. So, they're really living in cloud cuckoo land, some of these people.

And when we went to speak to him – he did all the speaking – he did not listen to us at all. He told us how great his clinic was all the figures and estimations that he had and he didn't listen to us. But, we're not finished with him yet – we'll be back, you know. It kind of really blew us away that day going up there, you know, the consultant with his suit.

Anyway, for a lot of drug users, their teeth are in a very bad condition. Now you might say they don't brush their teeth and I'm not very good at brushing the teeth – but I have a lot of false teeth. But drug users are very aware of their teeth, you know. And their teeth mean a lot to people.

But, they're finding it very hard to access dental care because they can't get a doctor to sign their medical card. Now, Fiona O'Reilly is working on a lot of areas around trying to access dental care – trying to access other medical issues besides having to get a doctor to sign this form because he is the gateway to people accessing the full range of medical care. And if a doctor doesn't like you well then you're not getting anything, you know. And that's not right that he should have that say.

Anything else? Anti-social behaviour and drug users getting thrown out of their houses. This is causing havoc in Dublin. And the amount of ill health associated with that – with people out in the streets not being able to access proper housing.

And when you haven't got proper housing and you haven't got that safe environment to go to a lot of bad things start happening to you spiritually, mentally and health-wise. And it's rampant in Dublin at the moment. Things are getting worse in terms of the homeless situation and health. There's an awful lot of work to be done there and I won't even start going into it here.

I hope that gives you an insight into the work that we're trying to do.

Thank you.

Richard Ajasa, Cairde

I'm Richard Ajasa and I would like to explain Cairde's programme which is two phases. We have a capacity building phase and we have a needs assessment phase for ethnic minority communities living in Dublin Inner City. And I'm a part of the programme, we're a group of 16. Actually, we are mostly activists in our communities and when we went into this programme we went in for the capacity building.

During the capacity building period we had our mindset, we really appreciate what we would be going into, what we would be going to day by day. Like looking at the social environment that really dictates or predicts our health.

And we went through this programme and the intention of this programme was to build our capacity to a position of community aid worker. We got capacity training for roughly eight to ten months and after that we went into the health needs assessment stage where we had training in research. The training we had was more or less focusing on the quantitative analyses of our health, of the social environment.

Actually we do less of the qualitative research with every day because this is what we live through. And we had a specialist come in to give us the training on the research tools.

For the needs assessment itself we must have had 13 or 14 interns in that project after we assumed the position of assistant community health workers. And this is a research which we decided on. We carried it out. We were in charge of the research ourselves.

The ethnic minority communities in Dublin Inner City are considered a hard to reach group and we need to tell our story ourselves. Our people need to go to talk to our own community. There's a good measure of trust. People can really come up to us and say this is what we are going through.

Even when we went into some of the problems that face undocumented migrants in the community, they were able to confide in us and say this is what we go through. There was zero access to social services.

The needs assessment programme – we have some preliminary issues surfacing in our research and I would like to go through the issues that were emerging during the research.

The first preliminary issues we have was immigration status and health. Immigration status – as a barrier to accessing secured employment and educational opportunity; as a barrier in accessing health and social services; as a factor in the stage at which people link in with health and social services and as a factor in people's perception of their own health.

The next one was accommodation. We found out that most of us live in private rented accommodation. We have very few who access the public accommodation which, in turn, probably guarantees you a longer tenure of your accommodation.

We found out many of us move within the space of one year from place to place. And you cannot complain much to your private agency or your private landlord. And that's difficult to get your children to try and go to school before you leave that place. I mean it was really affecting many of us.

And another problem we were facing was racism, discrimination and health. A significant number of people from minority ethnic groups do not feel accepted within the community and a small number within that have a feeling of experiencing racism and discrimination which has an impact on our sense of belonging, trust and well-being. This is a factor in how we learn about the availability of health and social services and how we access health and social services and the stage at which we access health and social services.

Another one was employment and education and health. That impacts at a very fundamental level. And it has a very strong link with our immigration status. Many of us we have experience, some of us have our formal education but your immigration status will dictate how far you go. How far you have a secure job. How far you are happy and healthy with your job and how far you can progress to the third-level education.

You have try to pick up the phone or go to the web-site of the central application organisation(CAO) – the first thing you see there is you have to get your status defined. Your stamp has to come to play here and if you are stamped first time or two stamps, three stamps, four, maybe many of us know what that means. Sometimes even some of the institutions doesn't even know what this stamp means and a letter from the Minister of Justice is needed. And sometimes we all know that it can take ages before you can get the letter from the Minister.

And some of us, we end up picking up part time work, probably we end up with a low paid job. You find out that you have to weigh up your options - lose your social service entitlements or you pay for the education yourself.

So people will end up remaining with the low paid job which is unhealthy for us and it has no future. And before you know it we have the trap.

Another problem is access to a range of health services. Ethnic minority communities themselves identify a wide-range of issues in their lives which cause anxiety, stress and depression other than a medical condition or the access to health services.

There is a poor uptake of many of the health services provided at community level, despite a good level of English and high eligibility among the samples.

Some of the challenges include lack of knowledge of services available and lack of understanding of different rules; lack of entitlement or restricted entitlement due to immigration status; financial cost of health services; poor out of hours services for those in employment; late presentation of health problems; lack of good communication and interpretation skills among service providers; and increased inaccessibility of the service and non-completion of treatments.

Addressing the determinants of health: we need to address all these issues that impact on our health; ethnic minorities must engage in new relationships with policy makers. This is part of the findings which we came out with.

And finding that there's a gap – there's no forum. Luckily many of us we are activists in our group. We have and with the help of Cairde and others, we had the training with CAN, we had a very dynamic infrastructure. We call it the ethnic minority health forum. We work hand in hand with groups now and probably that's given us a better way to really negotiate and to make our way through the policy process.

And part of the next step is to gain authority to engage in new relationships with minority ethnic groups in order to gain the benefit of community participation in decision making. This is with a view of collaborative actions to implement real changes which impact on the lives of minority ethnic groups, accessing services at community level.

The next phase of community development programme is action. We respond to the needs identified above in two ways.

First, it will create a dialogue between marginalised, ethnic minority communities and ask service providers to address the barrier in assessing health services.

Secondly, it will develop increased community participation in primary health care. We hope that will be achievable in the nearest future.

Thank you very much.

“Measuring the Right to Health – connecting local issues and global standards”

Professor Paul Hunt, UN Special Rapporteur on the Right to the highest attainable standard of Health

Good afternoon everybody. Very many thanks for the introduction. Many thanks to the organisers for the invitation and for working so hard to facilitate today. And, very many thanks for the panellists this morning for such graphic and compelling accounts.

I’m really pleased to be here for a whole number of reasons. But, I’ll just mention one of them. I think that PPR, this project, is doing some extremely important, complex and groundbreaking work. And it’s work that I and many others I know will benefit from and it’s work that I look forward to hearing more about today and in the coming months.

I call it groundbreaking because it concerns the right to participate and in the lexicon of human rights the right to participate is amongst the most important and it’s amongst the most misunderstood. And I think that your project will help us, not just in this island but, beyond this island. This project will help us get to grips with this important, complex right.

When I listened this morning I heard a number of issues. And this list isn’t exhaustive. I’m sure you can add to it. But I heard about a feeling of powerlessness, of not being listened to. I heard about stigma and discrimination. About health services being unavailable, but also health services being available but inaccessible to certain people. Certain people didn’t have access on account of various barriers, including poverty, immigration status and various other grounds of stigmatisation.

I heard about the insensitivity of some, not all, the insensitivity of some health professionals. And I heard about the inability to hold those in power, politicians and others, to their promises. I heard about not being able to participate – not being able to participate in a meaningful way and how the poor are disadvantaged in multiple ways.

I could go on but those are some of the issues that I heard this morning. And for me, one of the key features of these issues is that without exception they bear upon the enjoyment of human rights. Civil and political rights and economic, social and cultural rights including the right to the highest attainable standard of health. And I think it’s that connection between those issues and economic, social, cultural rights that I think you’ll be exploring today.

As I see it, human rights are a tool for social change. They do not provide magic solutions. Why not? Because there are no magic solutions. There are no magic solutions for injustice whether it’s political, economic or social. There is no alternative, it seems to me, but to struggle and in this struggle for social justice, human rights have a role to play.

We are very familiar with how civil and political rights, such as the right to a fair trial can be used to secure fair judicial procedures and we’re very familiar with how the prohibition against torture can be used to resist inhumane interrogation techniques.

But, what is new is the use of economic, social and cultural rights, the use of the right to adequate shelter, the right to the highest attainable standard of health. These rights also have a role to play for those of us who are committed to justice, fairness and a sense of common humanity.

And the governments and authorities in North and South have some binding, legal, international obligations. In relation to the right to adequate shelter and the right to the highest attainable standard of health. And as Inez said, this might be one of the best-kept secrets in Ireland. But it’s time this secret was let out.

And, in my view, we should use these obligations. We should use these legal duties to reinforce existing campaigns for social justice. And, for the most part, these economic, social, cultural rights do not demand radical new policies. For the most part, they will reinforce what has already been promised.

Can I briefly go back to basics? What are the foundations of human rights? The foundations include the sense of human dignity, the sense of the importance of human well being, of individuals and of communities. And, I note, in passing, that that sort of philosophical foundation of human rights is very close to the philosophical heart of the health professional and health professions.

And I think this is important. There is a lot of common ground between those working in human rights, the right to health and health professionals. And that’s an issue that perhaps we might return to on another occasion.

But, beyond these philosophical foundations – dignity and well being and so forth – what do human rights, like the right to health, what do they actually bring? And it seems to me that they bring three fundamentally important things.

First of all they bring entitlements. Not just needs, not just interests but entitlement. And out of these entitlements arise obligations. Not just ethical obligations but legal obligations of the state authorities to do certain things.

And out of these obligations there arises the requirement to institute accountabilities because the rights, the entitlements, and the obligations, become window dressing unless there are accessible, effective, transparent forms of accountability.

Those three things, the entitlements, the obligations, the accountability - they empower people. Human rights empower ordinary people and ordinary communities.

So, okay, here we have, dignity, well being, we have entitlements, obligations, accountability, empowerment. That still isn’t very practical. But it’s really important.

This is a long way from what we heard about this morning. It’s a long way from marginalisation, stigmatisation. It’s a long way from multiple disadvantage. It’s a long way from being ignored and silenced.

But in more practical terms – what does the right to the highest attainable standard of health bring? Now, I’m not going to give you a lecture. In the folder of papers you’ll find, in fetching pink, a short addition which sets out some of my work as the Special Rapporteur in the right to health. And there you’ll find references to my some 20 reports now that have been written on different aspects of the right to health. And if you are interested in a more detailed examination of what the right to health means you might look at one or two of those reports.

But, let me just mention some key features which I think bear very closely on what we heard about this morning. The right to health brings a right to health services for all, without discrimination. This is absolutely fundamental. A right to health services for rich and poor, for ethnic minorities and majorities, for children, adolescents and adults, for boys and girls, for people living with HIV-Aids, for drug users, for those with mental disabilities. There is a right to the highest attainable standard of health. There is a right to make accessible certain health services for all.

And therefore, the right to the highest attainable standard of health demands that special measures, special programmes, are taken to reach all groups. One shoe does not fit all. Special programmes are needed to reach different groups. Otherwise, the right to the highest attainable standard of health is not being honoured.

The right to the highest attainable standard of health also requires as much participation as possible in the health sector. Of course it's not expected that there will be participation in the most technical discussions but actually, they're relatively few.

And participation extends to devising policies and programmes. It also extends to participation in implementing policies and programmes. It also extends to participation in means of holding duty bearers to account.

Now, in my experience, there is often participation in the second one. That is, participation in implementation of programmes. It's less often that we have participation in the formulation of the policies, the formulation of the programmes and it's less often that we have participation in the mechanisms of accountability.

So if you want an outreach programme for drug users – secure their participation in the policy formulation, in the programme formulation, in the programme and policy implementation and in mechanisms of accountability.

If you want participation in relation to those living in poverty – you have to secure their participation around the policy formulation, around the implementation, around the mechanisms of accountability. The poor might be poor but they're not stupid. And they can have an active contribution to make in formulation of policy, implementation and accountability.

What else? Apart from this emphasis on discrimination and the emphasis on participation. Another emphasis on monitoring and accountability. The right to the highest attainable standard of health demands that there are effective, transparent and accessible mechanisms for monitoring and accountability.

Not with a view to sanction and punishment – that's not the main purpose of this monitoring and accountability. The aim of the monitoring and accountability is to identify what works, so it can be repeated, to identify what doesn't work, so it can be revised. That's the aim of the accountability. That's why we need accountability.

And there are, of course, many forms of accountability. One isn't going to work for one jurisdiction. You need different forms of accountability within the same jurisdiction.

There are what might be called general forms of accountability. Free and fair elections is a form of accountability. And, of course, this is absolutely crucial. Elections to local authorities, elections to health boards or whatever. There are those general forms of accountability.

In addition, from the human rights point of view one needs forms of accountability in relation to human rights standards. And here some countries have introduced right to health hearings. They've set up a public meeting and they've invited people in, government has come in and talked about the right to highest attainable standard of health in that particular community.

You also have as a form of accountability the international human rights treaty bodies that others have mentioned briefly, I won't go into. Another form of accountability are the courts. The courts are a form of accountability too. Another form of accountability, at least in some jurisdictions – I can't speak about Ireland because I don't know it well enough – but another form of accountability in some jurisdictions are national human rights institutions.

And, perhaps, time doesn't permit but there's some extremely important work to be done by national human rights institutions in relation to economic, social, cultural rights.

So here we have non-discrimination – critical in relation to the issues we heard about this morning. Participation is also critical. Accountability – monitoring and accountability – are also critical. And those three things demanded by the right to the highest attainable standard of health.

I need to briefly say something about progressive realisation. In international human rights law, the right to the highest attainable standard of health is subject to progressive realisation. This makes sense. Nobody expects a country overnight to realise fully the right to health. What the country has to do is progressively move towards realisation of the right to health for all.

The United Kingdom and the Republic of Ireland have both ratified the International Covenant on Economic, Social and Cultural Rights. And that talks about the right to health in Article 12 and it talks about in Article 2, this right being subject to progressive realisation. Things have to improve. That's all it means – things have to improve. Not at any old rate, not just bumping along just above the plateau. There has to be a certain trajectory established for the improvement of health services.

And, if things aren't improving then the state has an obligation to explain why not. Now, in order to do that you need, it seems to me, indicators and benchmarks – indicators and benchmarks. And I'm not going to go into this in great length. I've written three extremely boring reports on it. They are referred to in this fetching pink leaflet that I referred to earlier.

But, very, very briefly, if you want to capture progressive realisation – if you want an indication of whether the state is doing what it should be doing – you need indicators and you need benchmarks.

So what might they be? Let's say one of them might be maternal mortality rate and then you need a benchmark. Well, the benchmark is today's maternal mortality rate and then you need to know whether or not that rate is going up or down. And there's an obligation on the state to insure that it goes down.

From the human rights point of view however, you have to disaggregate the data because we all know that whilst the general data might indicate that things are getting better – when you disaggregate it you find that the general data masks things are getting worse for some communities. So the data from the human rights point of view has to be disaggregated.

In the case of maternal mortality, is the rate improving throughout Belfast or only in bits of Belfast? Is it improving throughout Dublin or only in bits of Dublin? Is it improving only in the urban areas or not the rural areas? That's the sort of disaggregated data that one needs.

Now, at the international level there's been a huge amount of discussion about whether or not we can just take your classic health indicators of which there are zillions and then take that label of 'health indicator' – and stick on a new label – 'right to health indicator'? And now I think it's fair to say that the general view is that, of course, we don't have to create a whole set of new indicators for the right to health. Of course we can take at least some of the existing health indicators. Probably maternal mortality would be one of them.

There are two conditions. Provided the indicator can be linked to a right to health norm – can be linked to Article 12 of the Covenant on Economic, Social, and Cultural Rights – can be linked to particular provisions in the Convention on the Rights of the Child, or whatever. So, by all means use the existing indicators provided you can make this link to human rights.

Second condition – it must be disaggregated. It must be disaggregated on the various grounds some of which I signalled earlier. Such as gender for instance and ethnicity and race and urban/rural and socio-economic group too.

But we do find when looking at the classic health indicators there are some big gaps, at least from the right to health point of view, there are some big gaps. From the right to health point of view, recall, I'm very interested in participation; I'm very interested in accountability. From the right to health point of view we need to know whether or not there is participation and is the rate of participation improving or not?

We need indicators that try and capture accountability as well. And I think that there's no escaping that actually community groups supported by others need to work on their own contextualised indicators. Not alone, of course, but supported by users, supported by health professionals and others.

And I have to tell you that this is what is being done in some communities. In the Philippines a few years ago they produced a book of their own on indicators to measure economic, social, cultural rights. I think the trick is to keep these indicators as simple as possible – don't have too many of them and use them to measure progress over time with a view to being able to hold the state authorities to account.

I need to mention one other thing. These obligations that the Republic of Ireland has and the United Kingdom Government has – these human rights obligations. They're not only subject to progressive realisation – they're meant to improve over time – they're also subject to resource availability.

Economic, social, cultural rights don't provide a blank check. Resources are limited, budgets are finite and when deciding how resources are to be distributed, however, from the human rights point of view, the situation of marginalized groups, disadvantaged groups, must be heard. And often their voice is not heard. And human rights requires that their voice is properly heard and properly taken into account so that when resources are distributed, when priorities are set, their interests and their rights are on the table as well as the rights and interests of dominant groups.

I will begin to close my remarks. I just mention one other tool that is being developed and I mention this in case it might be of interest and of use. There's some tools being developed now for impact assessment.

We're still struggling with it but before a government introduces a new policy it needs to turn its head to whether or not this new policy, this new programme, is going to have a good impact on the enjoyment of the right to health or is it going to have a damaging impact on the right to health.

And that impact assessment needs to take place before the policy is introduced – so it can be revised, if necessary. However, we need a methodology for this and it is now being developed. I just put that on the table.

Let me close with the following remarks. In years gone by the primary association we have with human rights campaigns are things like letter writing campaigns, things like naming and shaming, using slogans, campaigning in the streets. Now all those tools and techniques are really important human rights skills and methods and we need them in relation to economic, social and cultural rights.

But, there's another approach to economic, social, cultural rights as well. And for want of a better phrase – I don't like it – it's a sort of policy approach. That is to say getting the right to health and other human rights onto the policy table. Ensuring that they're integrated into policies and programmes so that they shape those policies and programmes because a policy that has integrated into it, human rights is more likely to be participatory, equitable, inclusive, robust, sustainable, evidence-based, and meaningful to those living in poverty. And that's why it's important to integrate human rights into the national and international policy making processes.

But to do that those techniques that I referred to earlier are not enough. The naming and shaming isn't enough, the slogans aren't enough, the letter writing campaigns aren't enough. We mustn't leave those behind, we still need those techniques but we need a range of other techniques. We do need indicators and benchmarks. We do need impact assessments. We do need to know how to choose amongst priorities. Some trade-offs are permissible from the human rights point of view and some policy trade-offs are impermissible.

Now the human rights movement, it seems to me, is maturing. It's now taking seriously the policy approach. Not just the naming and shaming but the policy approach and I think it's imperative that we use both.

I repeat, human rights should be used. They do not provide magic answers. They are part of a wider strategy and can contribute to the empowerment of otherwise disadvantaged individuals and communities.

It seems to me that society consists of a number of core social institutions. One is a political system, one is a court system and a core social institution is a health system accessible to all. Now a political system is underpinned by human rights, the right to take part in public affairs. The core social institution of a court system is also underpinned by human rights, the right to a fair trial. And, it seems to me, that a core social institution, that is the health system, is also underpinned by human rights, the right to the highest attainable standard of health and I urge you to use it in your strategies.

Thank you very much.

Roundtable Discussion - Selection of Questions

1. How do you break down the obstacles to access your human rights?

Paul Hunt: I think this boils down to how voices can be heard. Forgive me if I didn't catch your point correctly.

That is why participation is so important and the state has a responsibility to create forums and arena and mechanisms for drug users to participate – for people with HIV-Aids to participate – for undocumented workers to participate – for people with certain immigration status to participate. There's an obligation on the state to create those sorts of mechanisms.

When I say the state it might be that it's delegated down to local government and health boards or whatever. It doesn't matter. There's an obligation on the state to make these processes as accessible as possible. Is it messy? Yes. Is it difficult? Yes. Is it necessary? Yes.

It's not just right in principle, it's also right in practice because the policies and the programmes and the projects end up being better. So how are voices heard? Multiple ways have to be found and I'm afraid there isn't one neat answer to that very good question.

In some jurisdictions national human rights institutions have played a really good role in this respect. They've been brave and creative and imaginative and they've set up public enquires. They've appointed Commissioners to go around the country, sitting in town halls, putting notices in local newspapers, saying they want to hear from homeless people. And then they've written a report with recommendations and sometimes those recommendations have been taken up in different countries.

So there is a role for a creative, brave national human rights institution.

2. Should the right to health be included in the Northern Ireland Bill of Rights?

Paul Hunt: In my opinion, there's no doubt whatsoever that a Bill of Rights should encompass civil, political, economic, social and cultural rights. Otherwise, frankly, it's out of date. It's only half there. That's my view. I come at least in part from New Zealand and I'm sad to say that in 1990 there was a Bill of Rights enacted there which is only a catalogue of civil and political rights. And that is a source of regret to me. These days with an understanding of the inter-relatedness of human rights, a contemporary code of human rights has to include civil, political, economic, social and cultural rights.

3. Could you give an example of an intervention by communities or citizens which has resulted in a very practical change in attitudes and practices by statutory bodies which promoted human rights?

Paul Hunt: One of my formal missions was to Peru and there was leadership by a charismatic and brave Minister of Health.

She embraced the idea of the right to health and she did introduce certain changes in her ministry. For instance, the mainstreaming of the right to health. And she did take some brave steps. Particularly brave in Peru as she made emergency contraception available in public services. I think that she was partly able to do that because of the human rights analysis. She got into an awful lot of trouble with the Catholic Church it has to be said, in particular, Opus Dei, but she did it and she stuck to it.

I think this is an example, as it was partly the discourse and analysis of civil society organisations around the right to health that enabled her to take that political gamble. And also health information. Participation and accountability depends upon access to health information.

4. How can communities get policy makers to take rights seriously?

Paul Hunt: That's one reason why I mentioned the Minister of Health in Peru. It does need senior management actually to ensure this happens. And you do need leadership from – if not from the most senior politicians then from senior public officials. They've got a critical role to play in ensuring that there is legitimacy attached to the human rights discourse.

5. Does the right to health include the underlying determinants of health as well as health care?

Paul Hunt: The right to health isn't just about access to a doctor and a nurse. It's also about access to a safe environment and adequate water and adequate sanitation.

6. When will Ireland report on its progress around health to the UN Committee? What kind of resources are there for NGOs to write shadow reports?

Paul Hunt: There are now seven UN Human Rights Treaty Bodies consisting of independent experts and the UK and the Republic of Ireland have to appear before those bodies of independent experts and answer questions about what they're doing in their jurisdictions about human rights.

And those bodies, some of them do consider the right to housing and the right to health and the right to education. It's a weak form of international accountability in relation to economic, social, cultural rights, which does not add much but it adds something. It does provide a forum for civil society groups to feed in information into the United Nations so the United Nations can then ask frankly, tough questions, the appropriate questions to those State representatives when they appear before the United Nations.

A formal report is due to the Committee on Economic, Social and Cultural Rights from the Republic of Ireland reporting on the Convention on Economic, Social and Cultural Rights in June of 2007. Shadow reports are reports where civil society groups get together – the state will present its side of the story in the formal report and then shadow reports are an opportunity for civil society to give its version of events. Both are presented to the United Nations.

There are certainly not resources available from the UN for the preparation of shadow reports.

Michael Farrell: Somebody asked about the Covenant on Economic, Social and Cultural Rights - the Republic of Ireland's report has to be in June of 2007, though they are always late in putting in the reports. But when those reports go in it is possible for NGOs to put forward a shadow report, send it to the Committee and get the committee member so ask questions, to grill the government delegation when they go to Geneva to answer questions on their report.

The UN Committee may then issue a report in which they make criticisms of the government. Now the government won't necessarily, of its own volition, pay attention to that but they are very valuable lobbying tools. If you can say the UN Committee on Economic, Social and Cultural Rights has stated that access to health in the Republic of Ireland or in the UK breaks this international convention - it's an important and valuable tool in campaigning for better access to health.

Somebody asked, how do you do this? The best way to do it is to do it in coalitions. And that was done certainly, I've been involved with coalitions around the Convention on the Elimination of Racial Discrimination where an NGO coalition, put forward a very effective shadow report and then got a very good response from the UN Conventions. The same thing was done with the Convention on the Rights of the Child.

And the very fact of bringing together a coalition to do that sort of work is very valuable because it means that all the NGOs with an interest come together. And they have to adopt a platform and programme of their own on those issues which is in itself an extremely valuable thing to do. It raises their consciousness and gives them a sort of manifesto to use in the wider community to lobby for support. That is a way in which to mesh together the legal tools together with the political and campaigning tools.

7. To what extent should conflict be taken into consideration when attempting to solve problems on the ground?

Paul Hunt: One should absolutely take conflict into consideration when contextualising economic, social, cultural rights. Conflicts, whether it's between countries, within countries, whether it's gender based violence are issues that need to be taken into account, and States have responsibilities to address them too.

Eileen Weir: When you come from North and West Belfast, I think the conflict is very real for people there. There's a lot of our communities, three generations of the communities that know nothing else only conflict. It's bound to have some type of an impact on communities and individuals.

But we also have the other conflicts that are going on within the communities with the paramilitaries when they have their wars among each other four years to six years ago now when the conflict within the lower Shankill was at its worst. We're starting to see a bit of an outcome from children who were eight and nine at that time and are now 14, 15 and 16 and the groups that are out working with those children are now finding mental health illnesses with these children.

There was a survey done just at the beginning of 2006 with the Ulster Defence Regiment and it showed the issues, and the levels of suicide within that, which only started to show ten to fifteen years later after those involved had served in the UDR.

8. Is there a short-cut to winning rights?

Paul Hunt: If you know of one, please let me know [laughter from audience]. Sorry to turn it back like that. It is interesting that there isn't always a correlation between the amount of money thrown at a health sector and how positive it is in terms of right to health. I mean in the United States, there are over 40 million people, as we know, who are uninsured or underinsured. However, the amount of money thrown at that sector is much higher proportionately than in other countries. But some other countries do much better. So, it's not just a question of money. Sometimes it's a question of participation and accountability.

9. With regard to the Shankill area (North Belfast) – it was mentioned that money was being put into the Shankill specifically on health and education. To what extent were people consulted on their needs and had a say in where the money goes?

Eileen Weir: I'll tell you what I have been trying to do within the Greater Shankill and how that money actually came about.

That came about of the task force of the Protect Life Strategy document and the bereaved families within the Greater Shankill. They have a bereaved families support group and within that bereaved family there were carers of people who were self-harming. And they asked me to call a meeting with all the people who dealt with mental health within the Greater Shankill area which we did.

So the representative from the Trust who deals with the mental health and well-being on the Shankill called a meeting and sent out 30 letters to all these people who were working in the mental health field. There were six turned up. And this was for the families to present their strategy and their plan to try to reduce the risk of self-harm and suicide within the Greater Shankill.

And we got the message out also to the three networks that work on the Shankill, so all the networks were represented. We had no money at this time. We were doing this without anything. And we were asked because we had set up a group that was talking about the issues and we were asked what it was we needed?

And based on what was in the Protect Life Strategy document – based on the people who actually were suffering a lot of the self-harm and the suicide issues - that's how the money went to the Shankill.

We got £125,000 to set up 24-hour crisis centre. We are only a month old, and we have advertisement of the Shankill radio. We have a community slot on that and we're sponsoring the youth show. We have spoken to the youth.

And we are launching our project on the 16th December 2006 and we are calling on all community people to get involved because there's no one person or no one organisation or no one group can do this on their own.

10. Can you tell us more about human rights budgeting tools?

Paul Hunt: A good place to start is the work of FUNDAR [1], a Mexican NGO which has done some really interesting work analysing health budgets through the prism of economic, social and cultural rights.

11. Who decides what the highest attainable level of health should be?

Paul Hunt: What is the standard for the highest attainable level of health? Who decides it? Top down or top up? From the human rights point of view it needs to be a bottom up approach so far as possible. Of course, there will be some technical issues where people take advice from the specialists. Some people fear that this will lead to extravagance or wastefulness.

But, in my experience that isn't the case. If people have the information and if they understand that there is a finite budget and understand that the legal requirement is progressive realisation then they make responsible decisions which are inclusive and equitable and meaningful to those living in poverty.

[1] See http://www.fundar.org.mx for more information and resources. In the Republic the group CORI (www.cori.ie) do some interesting work in relation to budgeting and rights.

Reflections

Michael Farrell
Free Legal Advice Centres (FLAC)

This morning we heard Paul Hunt talking of the intersection between human rights and community workers. People working for disadvantaged people said that the relationship involved human rights activists listening to and learning from the grass roots community workers. And also the grass roots workers hopefully, learning something from the human rights activists. I suppose I fit more into the human rights activists bracket here. I have to say that I have learnt a lot from what we have heard this morning and it was very moving.

We live in the Republic of Ireland in the era of the Celtic Tiger and presumably in the North there's some sort of sub-Celtic Tiger or Leopard or something or other going on there.

We live with daily headlines of houses being sold for seven or ten million Euros and so on. Then you hear about the problems of recovering drug addicts in Dublin and their treatment in the Mater Hospital or you hear about the truly shocking statistics on suicide in North and West Belfast. That is a very healthy antidote to the picture that is portrayed in the media a lot of time. So, that was certainly very, very valuable experience.

Where I'm coming from is that I am currently a solicitor working with the Free Legal Advice Centre in Dublin which is an organisation that started up originally because there was no legal aid system in the Republic. There is now.

So what do we do now? We still run voluntary advice centres. There's still a need for that.

We campaign, at the moment, primarily around social welfare and access to justice issues. For the last year we have been running a project called Public Interest Law and Litigation which is an attempt to broaden out legal representation to disadvantaged communities, because it's very clear that the legal system doesn't really answer the needs of disadvantaged people.

They can't get access to it, it's too costly, it's too lengthy, it's too difficult to understand and lawyers are probably not very interested, anyway.

In an attempt to try and change this system, we have run a series of seminars in which we have tried to involve both branches of the legal profession, solicitors and barristers, the Legal Aid Board, all sorts of organisations campaigning around the rights of asylum seekers and disadvantaged communities.

There have been some developments. For instance, the Legal Aid Board in the South traditionally had a very stringent means test which meant only the absolute poorest of the poor could access free legal aid. And it confined itself almost exclusively to family law.

They have recently expanded the means test so that legal aid is now more generally available and they have also begun to widen the scope of the type of cases that they're prepared to take. And that is very important because these are state funded, free law centres that you can take your case to.

There are still a number of areas where legal aid is excluded. One of them is cases to do with property or land which excludes you if you are a tenant in a corporation house. They are also prohibited from taking test cases, that is cases that might actually change the law in the interests of disadvantaged people as opposed to just getting an individual benefit for somebody.

And that is one of the areas in which we have been campaigning and which is very important because no voluntary organisation is ever going to be able to supply the level of legal representation that is required for people to access their rights. So, it is important to make the state funded organisation answer up to some of its responsibilities.

Now, I would just say to everybody here who is from the Republic, that when you are dealing with issues that can be litigated go to the law centres. And if they say they can't help, appeal it because they have an internal appeals mechanism. And we have had some success already. It was never used before. People didn't know it existed and they certainly didn't tell you.

We have had some success already in getting Law Centres to take cases that they would not otherwise have done because it's appealed and because they know that there's a judicial review down the road if they don't take the case. And to give them their due, a new legal aid board was appointed five years ago and they were interested in broadening the scope of the board.

I believe another one is about to be appointed in the next day or so. I think we can take some credit for that because we've threatened to judicially review them if they didn't appoint it [laughter from audience]. We'll have to see what it's like.

Anyway, that is the sort of area in which we work. I'm also a member of the Irish Human Rights Commission and the Human Rights Commissions, both North and South, obviously have relevance to the type of work that the PPR is doing.

I should just give an example of the type of work that we are doing because it leads back to something that Paul Hunt said which I think is very, very important – which is that the law is 'a' tool, one tool, in an over-all campaign. The law cannot solve everything. In fact there are a lot of things it can't solve. And it shouldn't be used in isolation. That no matter what people may tell you a law case which is run in parallel with a political lobbying campaign is much more effective than a law case that is run in isolation.

FLAC is currently running a campaign about child benefit because in the South we have something called a habitual residence condition, where you can't get social welfare unless you have been resident within the state, legally, for a minimum of two years.

The social welfare authorities maintain that asylum seekers in the South are not legally within the state. So they cannot access the social welfare benefits. And it also affects quite a lot of migrant workers. Not all of them, but quite a lot of them.

Asylum seekers, in particular, have been deprived of child benefit since 2004. So, we're running a two-stranded campaign on that. We are taking some cases to the Social Welfare Appeals Tribunal and trying to challenge the legal basis for excluding child benefit in particular.

But, we're also running a publicity and lobbying campaign and there are a number of packs down at the back about this campaign which if anybody's interested that they're very welcome to take.

I think that's an example of how to do it. You use the legal route and you use the lobbying and political campaigning route, side by side. Because neither of them may succeed on their own but used together they have more chance of succeeding.

Having said that and having listened to the points that have been made - the question was raised by somebody about using these mechanisms. Paul Hunt talked about the International Covenant on Economic and Social Rights. I suppose this is something that is in-between litigation and purely political campaigning which is using international human rights mechanisms.

Paul talked about the International Covenant on Economic, Social and Cultural Rights which is a United Nations covenant which sets out a number of rights such as the right to health, the right to food, housing and shelter. There are a whole series of these covenants. He mentioned there are seven UN covenants – covenant on civil and political rights – covenant on women's rights, on children's rights –the right against racial discrimination – the covenant on migrant workers, which has not been ratified by either the UK or the Republic of Ireland That is something that we and the Human Rights Commissions are all campaigning for the ratification of because migrant workers are a huge issue in the Republic and, I gather, a huge issue in the North as well. When you get to the stage where I think a third of the population of Dungannon consists of migrant workers it is a big issue in Northern Ireland.

All those treaties and conventions contain rights which are relevant to disadvantaged communities, to the issues of poverty, to issues of health, to issues of housing and accommodation and so on.

To take an example, you might say, how's the Racial Discrimination Covenant relevant to that? It is relevant to Travellers seeking Travellers specific accommodation. In other words, Travellers are entitled to be accommodated in serviced halting sites if they want to because it fits in with their culture, rather than being forced to live in council housing estates.

There's a whole series of these conventions and there are a couple of European ones as well. There's a European Social Charter and the European Convention on Human Rights has a number of articles in it that can be used. The right to life can also be used to argue that you must have the right to the conditions that allow you to have a life.

The right to privacy can be used to assert the rights of disabled people. Also there is a new UN convention on disabilities, which the Irish Human Rights Commission actually played quite a big role in arguing for which neither government has ratified yet. And the Irish government did actually play a fairly supportive role in that convention which will give rights to disabled people.

These things are very well worth using but there's a caveat. They are not very enforceable. A number of them don't have any complaints mechanism that you can go to take an individual case. People will be familiar with the European Court of Human Rights, you can go to Strasbourg, you can take a case, you can get a finding against the government and the government may or may not pay attention to it but it generally does to the European Convention.

The UN conventions don't really have that. The European Social Charter does but it's a little complicated and has to be done through international NGOs or through the Trade Unions. But, it's worth using and we are trying to use it at the moment.

But on the whole, taking cases to those bodies is not the most effective route. What may be useful is the reporting mechanisms. Almost all of these conventions require the government to report periodically, usually every five years.

Somebody asked about the Covenant on Economic, Social and Cultural Rights - the Republic of Ireland's report has to be in June of 2007, though they are always late in putting in the reports. But when those reports go in it is possible for NGOs to put forward a shadow report, send it to the Committee and get the committee member so ask questions, to grill the government delegation when they go to Geneva to answer questions on their report.

The UN Committee may then issue a report in which they make criticisms of the government. Now the government won't necessarily, of its own volition, pay attention to that but they are very valuable lobbying tools. If you can say the UN Committee on Economic, Social and Cultural Rights has stated that access to health in the Republic of Ireland or in the UK breaks this international convention - it's an important and valuable tool in campaigning for better access to health. Used that way it's very valuable.

Somebody asked, how do you do this? The best way to do it is to do it in coalitions. And that was done certainly, I've been involved with coalitions around the Convention on the Elimination of Racial Discrimination where an NGO coalition, put forward a very effective shadow report and then got a very good response from the UN Conventions. The same thing was done with the Convention on the rights of the child.

And the very fact of bringing together a coalition to do that sort of work is very valuable because it means that all the NGOs with an interest come together. And they have to adopt a platform and programme of their own on those issues which is in itself an extremely valuable thing to do. It raises their consciousness and gives them a sort of manifesto to use in the wider community to lobby for support.   That is a way in which to mesh together the legal tools together with the political and campaigning tools.

I want to relate this project with the public interest law one that I mentioned. There's currently a small study group working on ways of getting greater access to the law for disadvantaged communities. That should report back fairly shortly. We will be holding a follow-up conference on that. And it would be very valuable for those who are interested here to come to that and to make the voice of the disadvantaged communities heard as well as the voice of the lawyers in that discussion as to how best to deliver law to poor and disadvantaged people.

And finally, I was delighted to hear Paul Hunt say that, you know, this is all a struggle. All rights are won by struggle and the law is one of the tools in a toolbox. Anybody who goes out to do a maintenance job in the house knows you need a toolbox - not just a single tool because you can't do the job with just one tool. You usually need several tools to do it. So, we need the tools. We need to use them together in order to achieve the result.

Thank you.

Jane Wilde
Director, Institute for Public Health in Ireland

The whole notion of reflections is to look at something and something comes back at you. At this stage of the day I'm seeing images, ideas, lots to be indignant about, lots to be inspired about but there's one flaw with reflections which is when you look you can actually see yourself back in it. And it's made me really think very carefully about my own position in relation to linking public health and human rights.

The job I do and what I understand by public health is this idea of health being part of not just public services, health services, but also the whole wide environment. And within the institute that I work in we've really taken the issue of inequalities as our driving force. And we've done that because I believe that is the most crucial issue, in terms of improving health.

I'm really interested in how the issue of equality and human rights comes together. And that's something that I'll definitely be trying to think a bit more about after this meeting.

I'm passionate about North/South cooperation. I'm passionate about public health and its' determinants and I'm passionate about trying to do something about inequalities in health. And I want to do two things really, first of all is to just recollect some of the words and quotes that people used this morning and what has stayed with me.

Obviously I can't do justice to the absolutely huge amount of thinking and ideas and work that went into that. But, Stephanie was using Gerard McCartan's words when he was told 'You're on your own'. Such an indictment of society and such an indictment of public services to have that said.

And Eileen Weir, when she was asked about why suicide was high said, well, of course because of paramilitaries, debt, housing and a lack of things to do. If you really want to improve health or human rights it has to work right across the board and everyone has a role to play. And that was an issue which Emily Reaper picked up when she talked about all the issues being enmeshed.

But another key thing that came through to me from what you said was about people being treated like everyone else and that made me think as well, I think about what people need and want. And Richard was very interesting because he turned the needs and wants into assets and capabilities.

And I think of a project involving the Community Action Network and four community groups. I think we also need to really grasp the issue of power at community level which is what's happening here.

So, five points I really want to make. First of all, is about the health services and health professionals. And as somebody who's worked in the health service most of her life and who is trained as a doctor, I just feel well, we have let people down. There is no way that I can excuse the kind of things that were said.

I would just like to put to you a couple of thoughts though just to add to the appropriate anger that there is about the way that people are treated.

The first is that I think that many people in the health service don't actually know what to do when faced with many of today's public health challenges. So there are huge issues about mental health, about obesity, about growing inequality where health care professionals are generally not trained, generally don't feel confident and generally don't know how to introduce the kind of changes that are needed to create a society that does not add to those problems. And I hope you'll see that not as an excuse but just to add to the other things that you might be thinking.

I also think that many people are just totally overwhelmed by what they should be doing, by what they have to do and by a lot of the changes that are happening around them. So I think there are huge coping ability issues in terms of what's been said today. And public services, health services and health care professionals and doctors, in particular, because they've been mentioned a lot and are crucial gate keepers so many services.

Second thing I want to mention is this whole idea of monitoring information accountability. I think as well as setting in place much better systems so that we know what is going on both at community level and at national level and international level, in terms of health and human rights that we also need much, much better systems to build up good information bases.

Obviously that's a subject that we could talk forever but I was very interested in that whole notion of tying accountability, information and local research together. And I think this project has a huge, huge potential to try and work with state agencies, to work with people who are interested in information systems and quality and standards to try and create much better and more integrated systems. So that's public services monitoring.

The third thing I want to mention is the issue of policies generally. And I was interested in what Paul Hunt said because he said, this whole idea of impact assessment, in terms of human rights impact before policies are set up. But I actually think it's also important, not only to think about new policies, but also actually the ones that we already have.

Because we have hundreds of policies and strategies that relate to, for example, health, that don't have a human rights component in them. So I think it's not so much the news ones that are coming on stream only, it's actually how are we going to assess the ones we have and ensure that we have human rights embedded in those.

I mentioned the idea of capabilities before and I think the whole notion of trying to link what is known, what is understood at community level through programmes, projects on health, human rights, community development, building that into the education and training of policy makers and health care professionals. It's such a gap.

I mean I'm not going to go on about my own experience but it had never occurred to me when I was going through my medical training that I could equally well, as I eventually did, gain my understanding of health and public health by working with communities in the most deprived areas. I mean that just wasn't the way it was when we were trained. So there's a whole shift in paradigm there in training I think.

And my final point really relates to relationships. Inez McCormack started by talking about how important it was to rebuilding relationships between programmes, projects, between policy makers and people working on the ground. And it just made me think much, much more about the interconnectedness of all that we do and the need for much better communication.

It also made me see a big flaw, as I mentioned before, in our own practice in the Institute of Public Health where I think we're doing really good, ground-breaking work in public health. But we are not properly building a human rights connection. So, I have a real hope that we could build a link between the work that we're doing in the Institute and in other public health bodies with all this work.

Because I think we could learn so much. And hopefully, we could also communicate about what we're doing because we divide our work into strands of research and information, policy and capability. So it fits so neatly, I think, with what we're doing. And I believe that issues about heath inequalities and human rights are entirely congruent.

The problem is that congruent: if you understand each world, but if you only understand one world which is probably where I am, it's really hard to make the connections.

So it's really just to say two things. A lot of the questions today were about how voices can be heard. Well, there's only one answer to that is that – listen. But, you also need to understand, or I need to understand, the language. You can't understand if you don't understand the languages that people are using.

So a lot to learn there. I've learned a huge amount.

Thank you so much for asking me to come. It's been so brilliant, important, complex, a struggle, but fantastic.

Thank you.

Comments and Responces

Paddy Kelly, Children's Law Centre, Belfast

My name is Paddy Kelly. I work in the Children's Law Centre which is based in Belfast. Can I firstly congratulate PPR on organising today. I think it's a brilliant event and I certainly learnt an awful lot and I'm going away with an awful lot to think about.

I want to throw out one challenge and one suggestion in terms of a solution. In the Children's Law Centre we do quite similar work to the work that Michael flagged up and we do it on behalf of children and young people. So in relation to a child's right to health we would give legal advice. We would take cases to access services. We do the policy and legislative commentary. We write reports to the United Nations Committee on the Right of the Child.

One of the challenges that we face which is maybe a challenge for all of us in this room and for government is that rights can only be realised if people know they have rights.

I think that's a challenge for all of us - to make the people who are suffering the greatest denial of a right to health aware that there is a right there that they can advocate for.

And I think we also need to put it to both governments that they have a duty to make people realise that they actually have a right to health. That's the first challenge.

The solution that we need to put to government is that in relation to some denials of the right to health and access to services, we need to look for solutions on an all-island basis.

Let me give you an example of this. There are small numbers of children and young people with very complex mental health needs, both in the South of Ireland and in the North of Ireland. In the South of Ireland, those children are being sent to Scotland and in some cases to the United States to access services.

In the North of Ireland they're also being sent to England and Scotland. This is at a great cost to both governments. They need to look at giving some provision for the small number of children on the island of Ireland which means their parents and brothers and sisters can visit them. They might be able to come home and visit friends.

I think we need to put this up to both governments. They need to look for some of the solutions on the island of Ireland by shared services.

Thank you.

Emily Reaper, UISCE, Dublin

Earlier I spoke about methadone treatment services and one thing we're coming across now is doctors detoxing people who are on large amounts of methadone, from say 140 milligrams down to 40 milligrams within a 10-day period because of behavioural stuff. Some of these people have psychiatric illnesses that aren't being looked after. Now, it's the only area of medicine where this happens because they are drug users. Drug users are falling ill because of the way they are being treated and they are resorting back to crime.

So how would you go about starting a campaign on that? We don't want to fight doctors because there are very few doctors working with drug users and we don't want to lose them. It's a rights campaign that we're looking to start.

Now, they stopped doing this for a little while beforehand when we brought it to their attention. But they have resumed their old ways again. We need to start something that will not fall back again.

Siobhan Boyle, West Belfast Suicide Awareness and Support Group

If there is one thing I would like people to go away with today it is to stop using the word 'commit' suicide. Because the families find it an offence. It hurts the family members when they hear people referring to 'committed suicide' because our loved ones haven't committed a crime. It was actually decriminalised in the 1960's. It's just something I'd like everybody to take away with them today.

Michael Farrell response:

Paddy Kelly was talking about awareness of right and that brought me back to a question that was asked in the morning session about the Bill of Rights. Somebody asked the question which got a very obvious answer. Should there be social and economic rights in the Bill of Rights that's being discussed for the North. The answer is, obviously, yes.

Under the Good Friday Agreement there is a provision for an all-Ireland charter of rights which the two human rights commissions are supposed to carry forward.

But, if we have an all-island Charter of Rights this is an opportunity to set out social and economic rights. The Irish Constitution which does have rights in it was written in 1937 when people had no notion of the type of rights we are talking about. And it's hard to amend. But, if you set out a Charter of Rights that contains the rights to housing, to health, to education, to equality– then that is a powerful weapon for measuring all legislation that's brought forward in either Parliament, to see if it conforms with it. And a campaign around that is a great way of raising people's awareness of rights and what they actually mean.

On Emily's point about treatment of drug users. How do you start a campaign? I think that what you do there is you try and get together a number of people who are interested in the issue – who know what the effects are and then you both go to people like Dr. Joe Barry who's the government drugs advisor. You go to the drugs task force. And you do some publicity around it. That seems like a simple issue – and I know simple issues are not always easily resolved - but it seems like a simple issue that should be easily resolved if you can explain it to all the parties involved.

And the big thing about that is that it doesn't cost a great deal of money. The huge issue in the South about anything to do with health rights is that if it's going to cost money the government doesn't like it and our courts are currently very conservative about this. They won't make any orders against the government that they think will cost the government money.

Jane Wilde response:

On Paddy's point about making sure people know more about right health - I couldn't agree more. I think it is as Paul said, a well kept secret. But, hopefully, things are changing on that.

On the second issue about North/South and strategic issues where there are perhaps a small number of people who need a service. It's really unusual for North and South to look strategically at planning services for anything. There is no strategic look at what services need to be planned together - that's not yet how it is. But, of course, it should be like that.

On the campaigning I think Michael said it all. Just two points I suppose - successful campaigns often happen not through well-planned campaigning but through a stroke of luck that a minister gets interested in an issue and sees the light. Or that somebody in the media does the same.

So, as well as the sensible, intelligent approaches you can also have a good bit of luck or non-luck.

And the last issue about what language we use in terms of different issues - yes, it is hugely important. I think that point is taken in relation to suicide. It also applies to lots of other things, as you know.

Closing Comments

Fidelma Joyce, Combat Poverty Agency

I work for the Combat Poverty Agency which is very privileged and honoured to be part of the Participation and Practice of Rights Project. From its inception we've been involved and it's a really, really exciting project and it's exactly what Paul Hunt said, I really believe it's groundbreaking. And maybe I'm going to identify some of the reasons why I think this project is so important based on what we've heard today.

Just to say from the Combat Poverty Agency's perspective, realising economic, social and cultural rights is absolutely core to tackling poverty and to overcoming poverty. So that's the essence of what we believe and what informs the approach to our work.

Participation, as we heard today, the right to participation is key to accessing economic, social and cultural rights. And participation is at the core of this project (The Participation and Practice of Rights Project) because it's very much about not just the rhetoric of rights but it's about making rights real and finding, together, ways to make rights real and to make social change.

As Paul Hunt said, it's one of many tools we can use to bring about social change. And I think what we've seen here today has been an important example of the way the project works because the most important and central aspect of the project and how if would be successful is by talking to people in the communities, by identifying the issues.

I suppose those issues were raised today. Those issues that relate to the right to health. And we've been able to share those experiences. The frustrations – the fact that the services let us down, not only in accessing the services but actually how the services treat us.

But we've also heard from groups which have worked through a rights process that they have made success – they have made gains. And as was said earlier it's a slow process, it's a struggle and achieving rights takes time. And I think what we've heard today, particularly from the speakers this morning, was they were also giving us inspiration in the sense of how they've taken on that struggle. Based on their own personal experience and how they have engaged the community and how the wider community has engaged with that struggle and that particular right.

What's also important today and it's something that Paul said as well, was around not only sharing our experience but also tapping into outside experience and that outside experience comes from everybody sitting in the room today. It comes from the speakers, it comes from all of those organisations and statutory agencies and government departments who are sitting here today as well. We are sitting in a dialogue, in a direct dialogue.

And one of the things that Paul was saying that it's about using a policy approach. Well, we're actually using a policy approach because we have a lot of the actors here today. Maybe the next conference we'll have more of the actors. We've had an opportunity to engage with Jane Wilde and with Michael Farrell who work for two key policy institutions, the Institute for Public Health of Ireland and the Irish Human Rights Commission. We're already engaged in that policy dialogue in terms of putting rights increasingly on wider agendas.

So, what are we taking away from today? We're taking away a shared experience, new information, new perspectives, new relationships and Jane spoke about those and I think new momentum because that's a very important aspect of this project too. That it is a demonstration project. It's testing how we can make rights real in two communities.

And we hope that today is an opportunity to share what we're learning so far with you. That we can get new insights, that we can come away today, reflect, maybe take on the challenges around developing the indicators that we can use to hold government to account that we can also measure the success and learning from this project. So that we hope that we can provide practical tools through this project that can be use and applied by other organisations throughout the life of the project.

And today we've started that process on the right to health. We want to continue that process in the near future on the right to housing and the right to accommodation. And through the various training programmes and development programmes that are being developed by the project we hope that these tools can be developed through dialogue with you and we can use those tools. And those tools can be multiplied and we can spread the use of a rights approach.

And I suppose just to say also from the Combat Poverty Agencies point of view, we're also through our own work funding and supporting groups to develop a rights approach. And we really want to, and I know that Amnesty International are sitting here today and they are doing that. And FLAC are doing that thorough the public interest litigation project. So, it's a lot of different entities working on rights.

And by bringing us together here today we can create momentum and we can make rights more known and more applicable and more used as a tool so we can actually realise the social change that we wish to.

So thank you very much to everybody here today.

Appendix 1
Biographical Notes of Speakers

Paul Hunt - a national of New Zealand, was elected in 1998 by the UN to serve as an independent expert on the UN Committee on Economic, Social and Cultural Rights (1999-2002). Between 2001-2, at the request of Mary Robinson, then UN High Commissioner for Human Rights, he co-authored draft Guidelines on Human Rights Approaches to Poverty Reduction. In 2002, he was appointed UN Special Rapporteur on the right to the highest attainable standard of health - the first appointment to this new human rights mechanism. As Special Rapporteur, he endeavours to help States, and other actors, better promote and protect the right to health. In his work, he has chosen to focus in particular on poverty, discrimination and the right to health. An independent expert, he undertakes country missions and reports to the UN General Assembly and UN Commission on Human Rights (now the UN Human Rights Council). Paul has lived, and undertaken human rights work, in Europe, Africa, the Middle East and South Pacific. In addition to his numerous UN reports on the right to health, he has written extensively on economic, social and cultural rights, including Reclaiming Social Rights: International and Comparative Perspectives (1996), Culture, Rights and Cultural Rights: Perspectives from the South Pacific (co-ed with Margaret Wilson, 2000), and World Bank, IMF and Human Rights (co-ed, 2003). He is a Professor in law, and member of the Human Rights Centre, at the University of Essex, England) and Adjunct Professor at the University of Waikato (New Zealand).

Inez McCormack is chair of the North/South Participation and the Practice of Rights Project. She is also joint chair of the Irish North/South Health Services Partnership. This brings together unions, employers and user groups in developing a model of collaborative partnership working to integrate equality and quality in delivery of effective health outcomes and to reduce health inequalities. Inez was the first woman to hold the post of President of the Irish Congress of Trade Unions. She has thirty years experience in the labour union and human rights movements as an activist and campaigner. She has received a number of national and international awards in recognition of her “outstanding contributions to the causes of human freedom and dignity“. She says the ones that mean most to her are the Aisling Community Award as Person of the Year (2001) and the Inclusive Ireland Award in 2002. Inez is a well-known broadcaster and writer and has contributed to “Being Irish” (2000), and “Truth Justice and Reconciliation” (2002) among others. Her writings were also chosen for inclusion in “The Field Day Anthology of Irish Writing.” (2002).

Gerard McCartan lives in North Belfast with his wife Carol and their children. Gerard’s and Carol’s son Danny took his own life two years ago and the death of their son is now subject of a Review instigated by Shaun Woodward MP the former Minister for Health, Social Services and Public Safety. Gerard is a member of PIPS (Public Initiative for the Prevention of Suicide and Self-harm), a group set up in North Belfast to support families bereaved through suicide.

Eileen Weir has been a community worker in North Belfast for many years. She has recently been appointed Co-ordinator of RAYS, (Reaching Across to reduce Your risk of Suicide) in the Greater Shankill which works to change the views, stigma and isolation associated with suicide and self-harm. RAYS gives support to individuals, families and care givers accessing information, training, education and signposting to other agencies. She has a special interest in supporting communities to work together on the issue of suicide and self-harm.

Emily Reaper is a development worker for UISCE. Her role is to advocate for drug users in the north inner city Dublin at policy level. Emily facilitated focus group discussions with drug users on health issues for the PPR. UISCE is a group made up of drug users, ex users and professionals who believe that the voice of the drug user is integral to the development of drug policy and in realising an effective treatment response.

Richard Ajasa was one of the participants of Community Development and Health Project from December 2004, then as one of the voluntary interns he participated in carrying out health needs assessment for ethnic minorities in Dublin’s North Inner City. At the moment Richard is Assistant Community Development & Health Worker (Community Employment Scheme) with Cairde.

Michael Farrell was a leading activist in the Northern Ireland Civil Rights movement in the 1960s and 1970s. He worked as a campaigning journalist in Dublin in the 1980s and became a solicitor in the early 1990s. He was joint chairperson of the Irish Council for Civil Liberties from 1995 to 2001 and has been a member of the Irish Human Rights Commission since 2001 and is convenor of its Racism and Immigration Committee. He has taken cases to the European Court of Human Rights and the UN Human Rights Committee and now works as a solicitor for Free Legal Advice Centres in Dublin and is involved in FLAC’s Public Interest Law and Litigation project.

Jane Wilde is the first Director of The Institute of Public Health in Ireland, set up to promote co-operation for public health between Northern Ireland and the Republic of Ireland. Jane studied medicine at Queen’s University and social medicine at the London School of Hygiene and Tropical Medicine. She has been consultant in public health in the Eastern Health & Social Services Board in Belfast, founding Director of the Health Promotion Agency for Northern Ireland, honorary lecturer in Queen’s University, Belfast, and a consultant for WHO. She has been involved in many Government policy groups, North and South, ranging from public health to housing, agriculture, consumer affairs and cross border studies. She is a visiting Professor at the University of Ulster. Her main interests are promoting equity in health, the social determinants of health, community development, healthy public policy, and building stronger public health systems.

Fidelma Joyce is currently Policy Liaison Officer with the Combat Poverty Agency, in addition to promoting the policy messages of Combat Poverty to diverse policy audiences, she is also working on economic, social and cultural rights, and health within the organisation. Fidelma previously worked for the European Youth Forum on policy issues, including women’s rights and on youth policy development in Central and Eastern Europe, and was at one time Women’s Rights Officer of the Union of Students in Ireland. She studied marketing and is currently completing a Masters degree in Equality Studies at University College Dublin.

Appendix 2
Summary of Round Table Discussion

What are the key problems that I or my group are facing on the ground in relation to health?

Information

- People don't know their rights – they don't know they have a right to health.
- Acceptance of a low standard of treatment and long waiting list because there is no education on the right to health
- Cultural barrier around benefit entitlements - people think they are a form of 'handouts'
- Difficulty for older people dealing with bureaucracy
- More clarity on how to apply human rights is needed
- Right of families to know the risks about medication being prescribed to their children

Engagement

- Difficulties in getting community people involved in understanding their rights
- Difficulties in engaging the statutory bodies on issues
- A catalyst for action is needed to motivate involvement
- There are problems in getting women involved in project: they are preoccupied with other problems and tend to put other priorities/others before themselves

Inequality

- Discrimination and stereotyping of drug users when there is a lack of services for rehabilitation.
- Unpaid family carers – can be bad for their own health
- Lack of transport in rural/urban areas, leading to isolation
- Unequal distribution of GPs
- Different groups have different needs

Accountability

- Absence of key indicators to measure health & health inequalities (quantitative & qualitative and lack of government statistics to inform health indicators) – need to find mechanisms to challenge inequalities taking place on the basis of health status (e.g. drug users, poor people)
- Accountability needs translating into practice. We should be proactive and challenge the system. Need targeted approach – skill people up.
- Who decides what the 'Highest attainable level of health' means? Often it's the consultant – top down approach.
- Decisions makers are making decisions based on administrative ease and not appreciating the problems
- Different levels of power between HSE, GPs and the community.
- Protect Life strategy is an example of the lack of accountability around policies. The Department is spending money but there is no community input and no accountability.

Access to Services

- Lack of mental health services
- Lack of access to information and services
- Problems in accessing dental health care for people with learning disabilities
- Lack of accountability across health services - problems begin with GPs receptionists and the difficulty getting access to an appointment. This begins the lack of basic human rights to the person in crisis and continues at A&E levels and across mental health service provision

Participation

- Problems in getting women involved in local health project – women are not prioritising their own health
- Lack of real and meaningful participation in consultations - decisions are already being made
- Capacity building issues – prevents participation
- Need to train community groups to participate fully – empowerment

Integrated services

- Lack of integration of services – e.g., dentists, doctors, consultants don't talk to each other
- Determinants of health inequality recognised but not dealt with by relevant sectors, e.g. housing, education, transport
- Health won't get involved with regeneration re: provision of services for increased houses.
- E.g. Health and Safety Executive not engaging with Regeneration of O'Devaney Gardens around identifying health needs

How might a rights-based approach to health be of benefit to my work?

- It could counter a lack of information on rights and information in an accessible format. Information is power and people do not have enough of this power
- It might stop the feeling of powerlessness – lack of knowledge and attitudes of health professionals
- Make people more forthcoming in claiming entitlements and seeking redress when not properly treated – especially to be treated with respect and dignity
- Integrate rights based approach to training/leadership
- Integrate rights argument in funding strategies

- Using rights language to promote participation
- Using rights training to overcome vulnerability
- Hugely beneficial – health would be a bigger priority if there is accountability
- Highlighting right to own health and well-being as a carer
- Right to information relevant to decisions you must take as a person or community
- Right to demand policy makers to engage, with assistance of PPR Project
- It is imperative that families, communities, voluntary sector and the statutory bodies be inclusive for the entire process of strategy implementation. To date families who campaigned around suicide tirelessly have a voice but no veto and no area of accountability.
- Brings recognition that it's a right and a standard – not something extra.
- Community development – participation – very empowering – awareness of language – it can transform context of work.
- It's about changing the way things are done – not just about getting something/anything
- Mechanisms to know – how you complain, demand rights
- Rights based approach might improve the access of groups to resources
- Would enshrine the right to information

What are the obstacles in adopting a rights-based approach or in realising the right to health? How might these be overcome?

- Community organisations willing to work with statutory agencies but this is a one way relationship
- Government departments: no/little evidence of joined up or holistic thinking
- Government can't or won't be integrated in its response to issues
- Lack of culture of using rights based approach (working class, Protestant, poor people)
- Rights based approaches threaten the power relationships of representative democracy
- Economic, Social and Cultural human rights are not ratified at national level so cannot be pursued through the courts and therefore lack of accountability
- Lack of immediate response by public bodies to health problems. Timescales deter people and can be used to dissipate the issue
- Public services, attitudes
- Government financial constraints – if you give people rights in law they will cost time and money
- Participation – how to how to break hold of politicians and other reps holding on to power
- Reluctance to talk about human rights (eg CBI, etc.)
- Attitudes by individuals eg pharmacists, doctors, etc (especially NI)
- How do you get people involved when struggling with everyday issues, eg. transport (rural especially), childcare
- Indicators should be included within strategy to enable communities reach the policy making process to eventually change policy to provide basic human rights for those in suicide crisis. No 'tokenism'. Full engagement with policy process.

- Obstacle – difficult to get right information on right of vulnerable group in a language they can easily understand
- Need for training on the right to health and the HRBA
- Unless we sustainably build capacity, people will not be able to speak for themselves
- Need to let communities come together and share to break down barriers and work together. Common interest in health
- How can we make sure we are all talking about the same thing?

Appendix 3
Summary of Conference Evaluation Forms

Question 1:
What was the best aspect of the seminar?

The majority of all participants cited the range and balance of speakers with direct experience and international expertise as being the best part of the event. It gave people a valuable opportunity to hear different experiences and to hear about the issues from different perspectives – from a North/South, legal, public policy, community and international perspective. The inputs from the community representatives were particularly enjoyed. The networking and information sharing that took place at the event were also highly rated.

Question 2:
What was the worst aspect of the seminar?

The lack of time to discuss all of the issues in detail was rated the worst part of the seminar, particularly issues raised during the roundtables.

Question 3:
What were your expectations of this event, and to what extent were they met?

Expectations were varied and included learning about the Human Rights Based Approach (HRBA), learning from community representatives, hearing about different experiences, networking, and getting new information and new energy. Peoples' expectations were overwhelmingly met, with a number of participants requesting additional information on the HRBA.

Question 4:
Have you been able to take anything from the event away to use in your work?

The answers ranged from useful information on indicators, contacts, new tools and ideas to the motivation to keep going. Another participant cited the importance of using lobbying and the law together to build a stronger campaign.

Question 5:
Do you have a better understanding of the importance and potential of indicators?

The majority of the participants had a better understanding but were looking for additional specific information about indicators. Many participants were particularly looking forward to seeing indicators in action and to learning from this practical phase of the PPR project.

Question 6:
What type of follow-up would you like to see from the conference?

Participants wanted a similar seminar next year to see if there had been any progress, regular updates on the work of the PPR Project, and more information on how to use the Human Rights Based Approach. Further information on the use of indicators was also requested by some participants. A number of participants also wanted some type of training in the community on how to use the HRBA.

Question 7:
Rate the usefulness of the papers provided

The majority of the participants found the papers to be very useful and interesting. Some participants did not have time to review the papers.

Question 8:
Rate the event, and suggestions on how to improve it:

Comments here were very positive ranging from very happy to excellent to 100% happy. The conference was rated as interesting, well organised, informative, insightful and inspiring by various participants.

Suggestions for improvements included allowing for longer workshops and group discussions.

Question 9:
Any additional comments

The convenient location was praised, as were the range of speakers with Paul Hunt and Emily Reaper getting particular mention. The organisers were thanked for their work

Appendix 4
Conference Registration List

Richard Ajasa	SPEAKER, CAIRDE
Sara Barkley	Cliftonville Community Regeneration Forum
Evan Bates	
Maggie Beirne	CAJ
Ina Broughall	Older Women's Network, Ireland
Kate Brown	PIPS
Nicola Browne	Participation and the Practice of Rights Project
Thomas Bundschuh	Transitional Justice Institute
Bronagh Byrne	Disability Action - Centre on Human Rights for Disabled People
Rachel Byrne	Bluebell Addiction Advisory Group
Eileen Campbell	Southern Group Environmental Health Committee
Noirin Clancy	
Paddy Connolly	CAIRDE
Peter Day	Community Foundation for NI
Avril Dennison	Participation and the Practice of Rights Project
Dessie Donnelly	Participation and the Practice of Rights Project
Rose Dugdale	Sinn Fein (Unionist Engagement Dept)
Mary Enright	PPR Project Management Committee
Terry Enright	UNISON Community and Voluntary Branch
Michael Farrell	SPEAKER, FLAC Public Interest Law and Litigation
Pauline Faughnan	Community Action Network
Dr Geraldine Fennell	Carers UK, Belfast Central Branch
Seamus Fitzpatrick	Impact/ Dublin Council of Trade Unions
Chrissy Flood	UISCE
Seamus Flynn	Markets Development Association
Felix Gallagher	Corduff CDP
Anne Gallagher	Older Women's Network, Ireland
Pat Gates	DICP
Aideen Gilmore	CAJ

Dermot Glackin	Public Health Dept SHSSB
Stephanie Green	Participation and the Practice of Rights Project
Kevin Hanratty	CAJ
Marie Harding	An Siol
Donna Heaney	Equality Commission for Northern Ireland
Seamas Heaney	Old Library Trust Healthy Living Centre
Mark Hogan	St.Vincents Trust
Elaine Houlihan	Combat Poverty Agency
Tanya Hughes	Ballybeen Women's Centre
Prof Paul Hunt	UN Special Rapporteur on the Right to Health
Tansy Hutchinson	NI Council for Ethnic Minorities
Lena Jordan	O'Devaney Community Development
Fidelma Joyce	Combat Poverty Agency
Oonagh Kane	Participation and the Practice of Rights Project
Paddy Kelly	Children's Law Centre
Pauline Kersten	UNISON Community and Voluntary Branch
Rosemary Kinahan	Special Project for Long Term Unemployed
Margaret Laffan	Bluebell Addiction Advisory Group
Seanie Lambe	ICRG
Wendy Lappin	Craigavon & Banbridge Community H&SS Trust
S Limbert	Old Warren Partnership
Dave Little	Health Service Executive
Stoifan Long	West Belfast Partnership Board
Stewart Love	Dept of Health & Social Services, Human Rights Unit
Russell Lucas	Craigavon & Banbridge Community H&SS Trust
Joe Lucey	Crinnan
Niamh Lyons	Bluebell Addiction Advisory Group
Thomas Mahaffy	UNISON
Monica Manning	Community Action Network

Declan Martin	Atlantic Philanthropies
Kathy Martin	Community Development & Health Network
Liam McAnoy	Community Conventions
Geraldline McAteer	West Belfast Partnership Board
Clare McCann	Chrysalis Women's Centre
Carol McCartan	PIPS
Gerard McCartan	SPEAKER, PIPS
Michael McCarthy	NWICAN
Fiona McCausland	Old Warren Partnership
Inez McCormack	Participation and the Practice of Rights Project,Chair
Pascal McKeown	Mencap
Sean McKevitt	Rural Community Network
Virginia McVea	NI Human Rights Commission
Jacinta Miller	University of Ulster, School of Law
Anne Moore	NICVA
Marie Moore	West Belfast Partnership Board
Olive Moore	Amnesty
Theresa Moriarty	
Sian Muldowney	ICON
Peter Mullan	Irish National Teachers Organisation
Fiona Murphy	CAJ
Nadine Murphy	O'Devaney Community Development
Stephen Murray	Investing for Health
Ruth Murray	O'Devaney Community Development
Maeve Ni Liathain	Participation and the Practice of Rights Project
Triona Nic Giolla Choille	Galway Refugee Support Group
Laura Niwa	Law Centre NI
Rory O'Connell	QUB Law School Human Rights Centre
Maureen O'Gorman	The Bytes Project
Trish O'Kane	Star Neighbourhood Centre

Fiona O'Reilly	UISCE
Eileen Pritchard	North Belfast Recreational Centre
Dr Joanna Purdy	Northern Ireland Public Health Alliance
Brenda Quigley	PhD Student on Primary Care
Padraic Quirk	Atlantic Philanthropies
Emily Reaper	SPEAKER, UISCE
Tom Redmond	Participation and the Practice of Rights Project
Aubrey Robinson	Radar Maker
Tanya Saunders	CAIRDE
John Scally	Sunflower Recycling
Rena Shepherd	Disability Action - Centre on Human Rights for Disabled People
Irene Sherry	Droichead an Doras
Gillian Stitt	Ballybeen Women's Centre
Sally Stitt	PIPS
Paula Tolan	Markets Development Association
Margaret Valente	Star Neighbourhood Centre
Tommy Valente	Star Neighbourhood Centre
Bernie Walsh	Sunflower Recycling
Theresa Watson	Chrysalis Women's Centre
Eileen Weir	SPEAKER, RAYS
Nicola Whelan	Ballymun Partnership
Liam Wiggans	New Lodge Housing Forum
Jane Wilde	SPEAKER, Director Institute of Public Health in Ireland