Participation and the Practice of Rights Project

Rights in Action: Changing Mental Health Services

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Mental Health Forum Report

PPR
Participation
and the Practice of
Rights Project

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North Belfast
Participation and Practice of Rights Project
54 York Street
Belfast
BT15 1AS
Tel: +44 (0)28 9032 6980
Fax: +44 (0)28 9032 8102
Email: info@pprproject.org

North Inner City Dublin
Participation and Practice of Rights Project
C/o ICRG
57 Amiens Street
Dublin 1
Tel: +353 (0)1 855 7207
Fax: +353 (0)1 855 4705
Email: info@pprproject.org

www.pprproject.org

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Welcome and Introduction from Chair and Panel
Inez McCormack, Chairperson

Participation and the Practice of Rights Project

Hello everybody. My name is Inez McCormack and I'm chair of the PPR Project and the session today. You're all extremely welcome.

We hope today will be useful and relevant to the groups who have struggled to make these issues visible and enable them to move forward not on the basis of their need but on the basis of their right as is the purpose of this project. So without any further ado I would like to introduce you to the panel.

Camilla Parker: Hello, I'm Camilla Parker and I work as a consultant on mental health and human rights. One in four of us, at some point in our lives, will experience mental health problems. I think it's very important to remember that because mental health problems can affect any one of us at any time in our lives. It doesn't discriminate at all. But, those people who do experience mental distress face a huge amount of stigma and discrimination.

Although in some countries things have improved, we still see that too often mental health services are not providing for people, for their individual needs in a responsive way or in a way that respects their rights. That is something that is hugely worrying and it's not going to go away.

I think across the UK, and in other parts of the world, we're seeing a massive increase of mental health problems amongst children and young people. Really, we're not doing enough to address their needs. We have to do something because it's very worrying that we still haven't got these things right. As I said, the stigma that is attached to mental health is enormous.

That leads me onto the second part of the project. The second part that I'm very interested in and really very excited about is the fact this project is about people looking at these very severe issues and trying to think about how they can take steps to address these issues.

The group are using a human rights based approach to do something and I think that's really what human rights about. It's about people and it's about thinking how we can address these massive concerns and do so in a positive way to really engage with mental health services and to think about what the issues are and how we can take steps together to really make a difference to people's lives.

So, once again, thank you very much for inviting me to this day's event and I'm really looking forward to hearing much more about the work of the group and engaging in discussion about that. So, thank you.

Tara Melish: My name is Tara Melish. I'm a human rights scholar and attorney based in Washington, D.C. in the United States. I specialise in the legal protection of economic, social and cultural rights, including the right to the highest attainable standard of physical and mental health.

In this respect, I have most recently been involved in the drafting negotiations of the newly adopted

United Nations Convention on the Rights of Persons with Disabilities which touches on many of the issues that will be discussed here today in the mental health field.

Most importantly, from the perspective of insuring the participation of users of services in the processes of determining what policies will be, how they're implemented and in the monitoring process around those procedures. This is something that international law speaks directly to and so it's very exciting to be here and to see how international law is being put into practice, on the ground, by real people.

It's something that I think really needs to be emphasised in the sense that we often think about international human rights law as something 'up there' – as something that is decided by international experts and has a defined content that other people decide and then has to be brought down to the local level.

International human rights law is actually entirely the opposite. At the international level there are enshrined values – principles. Those values and principals in the abstract need to be given substantive content and they can only be given substantive content on the ground by people who are interacting with the rights and who understand what they mean to their daily lives. And, they can insure that the policies and programmes which are put into effect at the local level are responsive to local problems. That is what the human rights struggle is about – how to make those values that we all understand as universally applicable to everybody meaningful in our lives at the local level.

That's why this project is so important and it's so exciting for us to be here to witness this project and then to be able to carry forth the lessons that are learned here to other struggles and other parts of the world. I think this focus on participatory approaches, human rights monitoring, performance monitoring of how governments are fulfilling their obligations, is something that is occurring in countries around the world – in struggles around the world. We need to learn from the innovative strategies that are being put into effect on the ground in different parts of the world.

This project here is something that we haven't seen in other parts of the world yet. There are many different projects around the world that are focusing on performance monitoring. How do we make sure the government is doing what it has said that it will do in international treaties?

What is different about this project is actually creating indicators and benchmarks and monitoring those with respect to specific problems. As opposed to monitoring specific conduct or specific programmes or policies that need to be implemented on the ground.

So, there's a great deal to learn from what is happening here and it's a great pleasure to be here as part of it. Thank you.

Christian Courtis: Good morning everyone. I'm Christian Courtis. I'm the Legal Officer for Economic, Social and Cultural Rights with the International Commission of Jurists, which is a human rights group based in Geneva. I'm originally from Argentina.

My programme of work is regarding what are called economic, social and cultural rights and that would include the right to health. Our job is basically trying to make these abstract declarations about rights that you find in international instruments, a reality. And, to think about what does it mean to speak about a right to health. What are the implications of this right to health?

For many years these rights were normally thought about cynically. They were put on paper but there was very little thought about they really mean in terms of implications.

So, our focus is trying to break down these general ideas into some concrete elements that should be assessed to see if the government is complying or not with its duties. So, part of the project touches on a number of the elements we are particularly interested in assessing, which is how people see themselves as right holders, who are the duty-bearers who are accountable for making these rights a reality, what is the extent of this obligation and how do you monitor the way in which these rights are complied with or not.

I'm also happy to be here because this is a groundbreaking project in lots of respects. Thank you.

Inez McCormack: Thank you very much. There are some apologies that I think are important to note. The First Minister has sent his apology, Dr. Paisley. He sends his best wishes for the success of the discussion. We've also had a similar message from Gerry Adams, who as you know organised a conference recently around these issues. We've had many other apologies. I'm just putting those two out at the moment.

We've also been deluged by messages of support. I just want to pick out a few of them because I think some of them are in your pack but I think it will give you an idea…I think we're starting, if we are permitted, with one which I think is very appropriate. This project, as you know, is working with groups on the ground to enable them to speak for them and go from the journey to 'need' to 'right'.

One of the groups we've been working with is on the right to housing – the Seven Towers Group of North Belfast, who some of you may remember. They stood up for themselves in June this year at an international panel and they have sent a message to the PIPS and RAYS groups saying, 'we want to wish them all the best for their event and for their work in using human rights to make changes to mental health services. Whether governments are keeping their promises on the human right to mental health or housing has to be measured in the communities most affected by these issues.' And, they have added these two important words, 'good luck'.

We've a message from someone who's worked with us since this project began and has been an enormous help in bringing the global and local together – Paul Hunt. I'm just using one sentence out of his message to make the clear point that all the panel members have made which is, 'mental health is among the most grossly neglected elements of the right to highest attainable mental health.' So, in a sense, he sees this work as crucial to making this issue more visible and on the basis of right.

A message, again, from Mary Robinson who has supported this project from the beginning, both in her capacity as UN Commissioner and also, her current capacity as Director of the Ethical Globalisation Initiative. She has made the point about this, which has been made both by the speakers – about setting the indicators and benchmark are being set by the communities on the ground to which government must respond. She also said to the panel of experts, 'you're a great panel'. She sent her best wishes to the panel and to all of us.

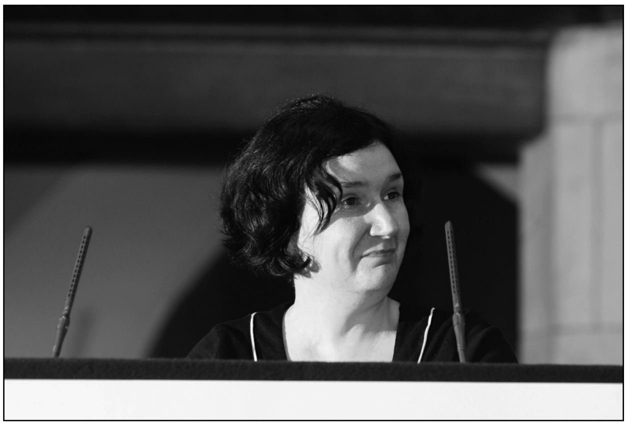
I also would like to welcome the Chair of the Human Rights Commission, Monica McWilliams, who is here today and thank her for coming. I'd also like to thank the President of the Irish Congress of Trade Unions, Patricia McKeown, who is here. Also Louise Beirne from Combat Poverty Agency in Dublin.

Also, we know there are a number of speakers who’ve come from the Republic of Ireland to talk about their experiences and you’re extremely welcome. You’re all extremely welcome.

So now we’d like to start the business. What I’d like to do is to ask Stephanie to introduce the DVD. PIPS and RAYS who are showing their work here today have all stood up for themselves in the most appalling circumstances with no space at all. They have challenged on the basis of their dignity as human beings and the dignity and right of their loved ones. This is a journey from ‘need’ to ‘right’. Stephanie will introduce the DVD which first puts in context the needs. As the day goes forward I think you will hear the journey to right on behalf of the groups. Stephanie.

Setting the Scene: Experiences of Mental Health in North Belfast

Stephanie Green, PPR Project



Thank you Inez. Good morning. As one of this mornings contributions to setting the scene I will outline firstly the objective need in relation to mental health issues and services with particular reference to North Belfast. Then I will introduce a DVD the PIPS/RAYS Rights Group did to highlight some of the problems mental health service users, their carers and their support organisations face when they use mental health services.

Just to begin, there are some quite stark facts in relation to suicide rates in North Belfast. The average rate per 100,000 in North Belfast is about twice the rate of the Northern Ireland average rate.

It is also where the highest rate of male suicide is found.

In October 2004 the North and West Belfast Trust, now part of the Belfast Health and Social Services Trust, identified the following gaps in mental health service provision in their area. There are 3.82 whole time equivalent consultant psychiatrists per 100,000 of population as against an average of 6.29 in the rest of the board area.

It is also worth noting that the Bamford Review on Mental Health and Learning Disability has reported that investment in mental health would need to be doubled to address the priorities highlighted in the Review.

As you can see from the slide in 2005 North and West Belfast experienced an underinvestment of approximately 2.5 million pounds compared to the average level of investment across the Eastern Board area.

Also, in general, only 8% of the health budget goes to mental health services and this includes all health and social services.

The mental health and well being of young people in North Belfast is of particular concern. As we can see, only 5% of the mental health budget is spent on child and mental health services, also known as CAMHS, despite 25% of the Northern Ireland population being younger than 18 years.

The Chief Medical Officer in 1999 raised his concerns as well. More than 20% of young people in Northern Ireland were suffering significant mental health problems by their 18th birthday.

As many will be aware here today, there are very high levels of deprivation in North Belfast. Out of the ten most economically deprived wards in Northern Ireland, two, New Lodge and Ardoyne, are in North Belfast. A further three, Falls, Shankill and Whiterock are in West Belfast.

Furthermore, research has shown that there is a strong link between suicide and deprivation. In Northern Ireland government statistics show that the average suicide rate in economically deprived areas is twice that of non-deprived areas.

For a long time government policy such as New Targeting Social Need and others, have recognised the necessity of targeting resources to where they are most needed. This was also reinforced by commitments recently in the St. Andrew's Agreement. Given the strong link between suicide and deprivation levels it offers government a further reason to live up to this commitment.

Thank you. That's my first part on need. I'll just go on now to introduce the DVD.

As mentioned at the start, the PIPS/RAYS Rights Group wanted to give you some of their experiences they have encountered with mental health services. They've done this through interviews with mental health service users, carers and their support organisations, which we'll see on the upcoming DVD.

The group would like to thank the following organisations for their help in gathering evidence about people's experiences of mental health services.

They are as follows:

Aware Defeat Depression

Ardoyne/Shankill Healthy Living Centre

PIPS Project

Shankill Women's Centre

RAYS Crisis Centre

And, of course, all the individuals who took part.

You may also want to take a look in your pack for, the 'Experiences Paper' and that gives further in-depth examples of what people have actually faced in trying to access services.

So, without further ado we'll take a look at the DVD.

Thank you.

Experiences of Mental Health Services DVD can be found on the 'Rights in Action: Changing Mental Health Service' DVD

Inez McCormack: Truth speaks, it can't be beaten. I think the rights process is about ensuring that the quiet dignity of what you've heard should be matched by an accessible dignity of service. It's not too much to ask. But, in a sense, that's what this discussion is about and that's what this work is about.

Could I now introduce Jo Murphy who is Coordinator of the PIPS Project to present her context?

PIPS – A Community Response

Jo Murphy, PIPS

PIPS are delighted to be here today to talk about where we came from and the work that we're involved in.

PIPS is now actually going into its fifth year. Previously I worked as a health and social wellbeing development officer with North Belfast Partnership – so part of my role would have been to look at different health priorities within North Belfast.

I had also known somebody that actually died by suicide. So, from a personal point of view I really felt there was a need for something in the community. So, I asked whether we could make it a priority in our area of work.

Suicide was very much one of those issues that sat over there and nobody really wanted to talk about it. I see suicide very much now like 'the big C', as it was known years ago, don't talk about it because you might catch it. But, you can see a big shift and a big change over the years and certainly since PIPS has been up and running.

The name PIPS came about when I came into contact with Phillip McTaggart who had lost a son to suicide. I had read a small article that he had written in our local newspaper, the North Belfast News and he was encouraging, particularly young people, to go and seek help. So, if anybody was feeling depressed or low, that it was important that they spoke to somebody about it.

Philip McTaggart's son was known as Young Pip. He was 17. He was a really good-looking guy and had plenty of friends. Everybody was left within that particular community asking – why did he take his own life? So there were a lot of concerns within the area for other young people as well.

So, after doodling about, we came up with PIPS and PIPS stands for Public Initiative to Prevent Suicide and Self-Harm. It was basically to let people know as well that there was person behind this name. That this was a very real issue.

I think key to this work is partnership working. We can't, within PIPS, do things on our own. I see it very much as a football pitch. We'll have the best of players on that with us. So, this really, after negotiating with the Housing Executive really was a very practical thing and it was partnership working at its best.

It's about breaking down barriers, particularly for young people, encouraging them to seek help and also, letting them know what help is out there as well. It's about young people because sometimes we underestimate them. These were smashing young people that came in. One particular young person in that group had lost a friend to suicide and they had actually wanted to put something back into the community and do something for PIPS. It's about young people making a difference and it's also about promoting positive mental health.

Our Mission Statement within PIPS is, 'PIPS aims to save lives and support those affected by suicide and self-harm'. Our aims are to raise awareness and to educate and we're delighted to be out here and to be raising awareness particularly around this issue.

PIPS works to encourage from within the community the promotion of emotional health and well being. Our aims are to provide support for those left behind. One of the things we did and identified in the beginning of PIPS was when you actually lose someone to suicide there's nobody that raps your door. You have a lot of friends and family at that time but a few weeks after that people start going away.

So one of the things we felt there were gaps in, certainly within our community, was to actually go out to people who had lost someone to suicide. We produced a bereaved through suicide pack and, also a card with ‘thinking of you at this difficult time from all of PIPS’. Again, research has shown the need to connect with the family because when you lose someone to suicide you’re in high-risk suicide group as well. So that immediate connection means that there is a lifeline to something and they feel that they’re connected up to something.

And the other forgotten group is carers. I think that’s something that has really been highlighted to us within PIPS. When you’re actually living with somebody who has attempted suicide there’s that eggshell walking that goes on in family units and with carers as well. So they need support. They’re a forgotten group as well.

One thing I would really love people to take on board is that when someone is lost to suicide families are actually very offended by the term ‘committed suicide’ because it links it to a crime. So we prefer to use the terms, ‘died by suicide’, ‘completed suicide’ or ‘taken his or her own life’.

If you look at each year approximately one million people die by suicide worldwide. In the North of Ireland last year 291 people died by suicide. There’s been a 37% increase in 2006, there were 213 that died the year before.

More young people die by suicide than on our roads and, yes, I do agree and I think we need to campaign. But it’s not on the TV, it’s not on the billboards, it’s not on the buses and, I think we all have a responsibility to do something about that.

Approximately two people take their own life each day on this island. Last year it was over 500 in Ireland as a whole. Worldwide suicide ranks as one of the three leading causes of death. People die by suicide worldwide every 40 seconds.

Deaths by suicide are only part of the problem. Attempted suicide is estimated to 10-20 times more frequent than suicide, particularly among young women. This is something that we need to talk about because when you look at those sorts of figures it is a very real issue within all our communities.

Friends of the deceased there are also in the high-risk vulnerable group. Particularly if it’s been a young person and they’ve been quite popular within an area as well. Extended families need support too so it’s important that we encourage self care because if they’re looking after the immediate family it’s important that their mental and emotional well being is being looked after as well.

Every death by suicide potentially impacts in anything up to 100 people and possibly a lot more. I think we’re really underestimating that. It’s like throwing a stone in the water – it just a real ripple effect is created by one suicide.

PIPS now has a number of satellite groups across the north of Ireland. These have come about because of families who have lost loved ones and have heard about the work that we’re doing and have said, “how can we set a PIPS up in our area because there really isn’t anything at grass roots level”. So we have PIPS in Newry, Newcastle, Cookstown, Downpatrick, Ballynahinch, Lurgan, Derry and at the minute we’re doing a lot of work with Portrush, Craigavon, South Armagh, Holywood and Carrick.

Our partners – PIPS have formalised links with community, voluntary and statutory agencies in an attempt to gain immediate accesses to much needed services. I do think that has been key to the work that we do within PIPS and is really working in true partnership and trying to gain immediate access for people. Because when people present to us in crisis there's no point in me saying there's a six to eight month waiting list. People have come very distressed and want services there and then. Again that sort of works and I'm not really all that nice all the time, if I want something for somebody I'll just beat doors and shout.

Financial worries also put an awful lot of stress and strain on people's mental health. We actually have an advice worker who comes into PIPS one evening a week and would see people in the evening because of the whole thing around confidentiality. It's not nine to five; it's about opening our doors outside of hours for people's needs.

PIPS have taken referrals from a wide variety of sources. You have GPs, social workers, home-based treatment teams, probation officers, clergy, hospitals, teachers and the PSNI in there just to name but a few.

This is very emotional and very draining work as well. One of the things that we identified is to make a big investment in training for people. Some of the examples of that would be, obviously, the Assist Telephone Help Line Training, Cruise, Bereavement Counselling Training and Competent Helper to name some.

We were delighted and very proud to have actually won the regional award and moved on to win the National Training Award for Innovative Training on the model used in North Belfast.

I'm nearly finished because I just want to tell you all about PIPS and whatever but will probably be getting a cue to keep quiet soon.

When PIPS first started we went down to the City Hall to hand out leaflets. And a lot of people would throw them on the ground or say 'no, I don't need that'. Yet, you can see over this last few years and because of all the lobbying and campaigning there has been a big shift in this as well. I know it's very slow and very frustrating but you can see a big change in people's attitudes as well.

PIPS has celebrated its fourth memory tree of lights – we'll be doing that in December again. Every day is hard when you lose a loved one to suicide but in particular birthdays and anniversaries and Christmas which is very much a family time. And we wanted to do something in North Belfast.

So the first year we put a small article in our local newspaper just inviting people who had lost a loved one to come along and put a message on the tree to their loved one. Just to say that they hadn't been forgotten.

I always remember and it still makes me smile because I relive the moment – I remember putting out about 20 seats in the 174 Trust and Phillip said, 'Jo, wise up, we're never going to get 20 people'. Over 300 people came and queued. It was the most moving thing for me personally that I've ever been a part of in my life. I remember one mum coming over who had lost a son 27 years ago and she actually said it was the first time that she'd been with other people who have been in the same position. I knew then we needed to keep going with this and I'm delighted that we have.

I'd just like to thank you for listening to the work of PIPS and for being here today. Thanks a lot.

Inez McCormack: Thanks very much Jo. I remember talking to PIPS people a few months or a year ago in terms of having to argue for funding – why, why? This work is actually about realising the right. It's actually about realising the kind of response, which actually prevents suicide and actually enables people who are affected to move forward. This is a flexible and imaginative community response, which should be available as a right.

So, now could I introduce Gerard McCartan who will talk about how the PIPS/RAYS Group has used the rights based approach and describe his and Carol's own journey from pain to change.

The PIPS/RAYS Rights Group: Using the Human Rights Based Approach

Gerard McCartan, PIPS/RAYS Rights Group

Gerard McCartan: Good morning. On behalf of the PIPS/RAYS Rights Group I would like to thank you for coming today to listen to our personal experiences of mental health services and about our aim to make the right to the highest attainable standard of mental health a reality for everyone.

My wife Carol who is a member of PIPS, Kate and Jean are here today. We lost Danny to suicide, Danny was our son and he was 18, on 11th April 2005 – he would have been 21 two days after Christmas this year and it will be very difficult for us. When Danny was ill we had so many battles to get suitable services for him. Struggling to get him in to this service and he was taken out the other service. The day that Danny died he asked the CPN could he go into hospital. He wanted to get his head cleared and he was told, no. There were no beds.

I'll rewind back a wee bit and just tell you briefly about what we went through. Danny self-harmed. He went to the GP, me and his mammy went to the GP, there were wee scratches in his arms and we were told that it was a fad, it was a phase and that all young ones are doing it. And, I can remember it was a hot summer's day and we come out of that surgery and I was looking at all the kids to see if they all had cuts on their arms and there was none.

Danny went back to the doctor himself and was prescribed anti-depressants and Diazepam and a few months latter he took an overdose. And, funny, at that time we were very concerned and PIPS had organised an information night in Ardoyne, where we're from and we went over that information to find out why people self-harm. We went back that night and Danny was found with an overdose.

He survived and he was put into an adult ward. There were no services in North and West Belfast for children and adolescents. We couldn't believe it and he was put up in Knockbracken, an adult psychiatric unit. He cut himself in there too and he was put on an observation watch.

He was in the health system for eight months and in eight months we were pushed from here, pushed from there, do this, do that. As I said, the day that he took his own life – after the CPN told him no – that was at half two and at half nine Danny was found dead.

It was then Carol and I started the process of trying to get answers to some of the problems we had faced trying to get Danny the right help. This is ongoing today as the Independent Review of Danny's case only came out quite recently. Danny said one time – 'if he ever got better he wanted to join PIPS and he wanted to go and be a voice for young people and tell them what the services were like here'. Unfortunately, Danny's not here today so me and his Mammy do it. That is our inspiration and why we continue to struggle.

We got involved in the Rights Group last October with others from PIPS and RAYS. Most of us were already involved in trying to improve mental health services with our respective groups and had been successful along with other groups in our calls for a suicide prevention strategy – 'Protect Life'. We also realised that this was probably just going to be the start of much longer campaign to actually get that strategy implemented so that it had a real impact in our communities. We wanted to know as much as possible about how we could change things for the better – and knowing about rights and how to use them seemed to us one important way of doing this.

So how did we do this – we did the development programme with PPR. It was no problem people coming from both groups coming together as we already had been working together on a number of issues beforehand including successfully campaigning for the Protect Life Strategy. The development programme included confidence building with Mary Enright, I don't know if Mary's here, which we all really enjoyed. We moved on and we made links between our issues and human rights. Finally we researched for a number of months to the extent of the issues that we had identified and which had affected other people through the surveys and the focus groups. Also, we started to think about ways to access the right to health.

Right now a lot of attention is being made to mental health issues a lot of policies are being put in place. The North and West Trust and the Mater Trust are part of one big trust now. We've a local assembly up and running and government committees have been put in place. There are a lot of committees and a few people we've been talking too find this a bit confusing.

What we have found in a different approach about rights is that people on the ground most affected by the issues should be setting the agenda about what is to change, how it will change and when it should change. We would like to be involved in the change.

Thanks very much. Thank you.

Inez McCormack: Thank you Gerard. I'd now like to introduce Laura Niwa from the Law Centre who is going to put the broader policy context as Gerard has said rather tactfully we're coming down with policies and reviews at the moment. The question is what are they and then how do we move on to make sure that they work on the ground? Laura.

Linking Issues to Policies

Laura Niwa, Policy Officer, Law Centre NI

Laura Niwa: Thank you. Thank you to the PPR project for inviting me to participate at today's event.

I am very encouraged by the commitment and dedication shown by the PIPS and RAYS rights groups and the demanding work that has already been undertaken by them in this vital area of mental health awareness raising.

I hope to share with you this morning some of the main policy developments in Northern Ireland in recent years that aim to highlight, address and correct the imbalance that has developed over the years in relation to mental health services in Northern Ireland. Given the rights based focus of the groups present here today I will place particular attention on the issues of participation, accountability and measuring the impact of these policies as a way for us all to learn where to go from here.

Background

International and domestic law recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. International guidance on what this means has specified that the right to health contains both freedoms and entitlements – the right to be free from interference, the right to participate in decision-making processes and the entitlement to a system of health protection that provides people with equality of opportunity to enjoy the highest attainable level of health. People with mental disabilities and representative organisations should therefore be involved at all stages of the development, implementation and monitoring of programmes and policies relating to mental health.

As we are all aware there has been a definite growth in the awareness of and public profile allocated to issues related to mental health in Northern Ireland in recent years. For too long mental health has been seen as the Cinderella of health services and the impact not only on those with mental health problems but their families, carers, friends and community has been all too often ignored or swept under the carpet.

While there is still some considerable way to go and while we are all saddened that it has taken the unprecedented growth in attempted and completed suicides within Northern Ireland and the media highlighting various cases of the abuse or neglect of the human rights of many with mental health issues to place mental health firmly back on the public agenda, there are moves to redress the imbalance suffered by mental health services in Northern Ireland.

We are all aware of the statistics associated with mental health in Northern Ireland – with mental ill health affecting one in every fourth person and costing an estimated 3-4 percent of the gross domestic product, mainly through loss of productivity. Northern Ireland has the highest level of benefit claims as a result of mental ill health in the UK. But the real costs goes far beyond the economic and failing to address mental health issues impacts significantly on the quality of life of individuals, families and communities.

Bamford Review

The Bamford Review of Mental Health and Learning Disability was the first ever comprehensive review of policy, services and law for people with mental health needs or learning disability in Northern Ireland. The findings of the Review which published its last report on a Comprehensive Legislative

Framework in August this year, have provided compelling evidence of the need for comprehensive reform and modernisation.

One of the key components of the vision underpinning the Bamford Review is 'valuing those of us with mental health needs or a learning disability including rights to full citizenship, equality of opportunities and self-determination.'

The need to ensure full participation was one of the main principles of the Bamford Review and it was committed to 'partnership with users and carers in the planning, development, evaluation and monitoring of services'.

The Bamford Review recognised early on that in Northern Ireland there has been a clear deficit in the involvement of service users and carers in the development of key policies and service reform. The Review sought to address this imbalance by setting up working groups within 10 main areas. These working groups provided for a comprehensive cross-section of individuals involved and impacted by mental health issues.

The need for the recognition of the importance of participation was a key theme in all the Review's reports and highlighted the lack of participation currently in place in mental health services and policy development in Northern Ireland in all key areas including Child and Adolescent Mental Health Services, Services for Older People, Services for those with a Learning Disability and Forensic Services to name but a few.

As already mentioned the Bamford Review's final report focused on the need for a comprehensive review of mental health legislation and called for the introduction of legislation concerning people who lack the mental capacity to make decisions for themselves, and their carers and people who work or engage with them in Northern Ireland.

Mental health law and mental health policy are closely related. Mental health law can influence the development and implementation of policy, while the reverse is similarly true. Mental health policy relies on the legal framework to achieve its goals, and protect the rights and improve the lives of persons affected by mental ill health.

Our current Mental Health Order dates from 1986 and it is interesting to note that although 75% of countries around the world have mental health legislation, only 51% have laws passed after 1990 and nearly a sixth have legislation dating back to the pre-1960s. Legislation in many countries, including our own, is therefore outdated and in many instances can act to take away the rights of people with mental health issues rather than protecting those rights.

Work on new legislation for those who lack decision making capacity for Northern Ireland began pre Bamford but was halted while the Review was completed. We trust that now the recommendations are complete that this work will begin again and the Civil Law Reform Division will take on board the principle of participation and ensure that any draft legislation or recommendations for legislative reform are fully and comprehensively consulted on in an appropriate and all inclusive way.

The recognition of ongoing participation in the implementation of the Bamford recommendations has also been taken on in various forms. Belfast Health and Social Care Trust as part of its consideration of the implementation of the Bamford Review's recommendations are in the process of being the first Trust to appoint a service user as paid member of staff to its board. This is a significant step in recognising the expertise and value of service user participation and involvement in developing services and policies to meet the need. This move, which we hope may be mirrored by the other Trust's ensures a level of accountability for the implementation of the Review's recommendations.

Furthermore the recently established Mental Health and Learning Disability Board have also spoken of its desire to model participation and accountability as it begins its work. The Board was also developed following the Bamford Review, and it has announced plans, with the support of the Minister of Health, Social Services and Public Safety to reconvene or re-establish similar working groups as modelled by the Bamford Review to assist it in its monitoring and reporting to the Minister and the Department of Health, Social Services and Public Safety regarding the development and implementation of mental health policies.

The Board will be a useful tool to hold the Minister and the Department to account regarding the implementation of the Review's recommendations and any future policies initiatives. As such it is hoped that the Board will engage at a community level with many of us here present to ensure that the views of those most affected by mental health policy in Northern Ireland are taken forward.

Protect Life: Suicide Strategy

Moving on from Bamford, Northern Ireland has also seen the development of numerous policies related to the prevention of suicide. While this was a long time coming families bereaved by suicide were instrumental in the achievement of Protect Life the suicide strategy for Northern Ireland.

The strategic aim of the strategy is to reduce the Northern Ireland Suicide rate, particularly among young people and those most at risk. The strategy envisages a 10% suicide rate reduction by 2008.

As many of you here will be aware a number of the strategy's key objectives go straight to the indicators set by the PIPS/RAYS rights group. These include the need to ensure early recognition of mental illness, and to provide appropriate follow up action by support services and the need to provide appropriate training for people dealing with suicide and mental health issues.

One of the key components of the Strategy was that bereaved families sat on the implementation body of the suicide strategy. Furthermore the strategy contains a commitment to consult on an annual basis with those bereaved by suicide, survivors and local communities in Northern Ireland when carrying out the progress review of the implementation of the suicide strategy.

The Strategy also recognises the benefits from sharing with and learning from best practice and to help facilitate this, an All-Island action plan has been developed, and a Five Nations Working Group has also been established to assist with this objective. Earlier this month Health Minister Michael McGimpsey attended the third meeting of the Five Nations Working Group meeting with representatives from Scotland, England, Wales, and the Republic of Ireland to discuss sharing best practice in relation to suicide prevention.

However, despite these positive steps the experiences of consultation and involvement in decision-making bodies have varied. Concerns were raised at the development of mental health programmes launched earlier this year without recognition or contact being made with the families' forum. It is clear that communication to all parties involved in the development of mental health policies needs to increase and a firm commitment to the participation process needs to be made by the public, private and community and voluntary sector.

The Health, Social Services and Public Safety Committee have also taken on board this vital issue and launched an inquiry into suicide prevention in September this year. As part of the inquiry the Committee will assess the scope and appropriateness of the Department's strategy 'Protect Life: A Shared Vision'; examine the level of stakeholder participation; examine the level of services and support available to promote good mental health, to prevent suicide and self harm; and to support those effected by suicide; and consider what further action is required, taking account, as appropriate, of experience elsewhere. The Committee is currently considering the responses received and we await with interest the result of the inquiry.

Complaints in the Health and Social Services

With all public policies there must be a level of accountability to ensure that individuals have a right to access a remedy when things go wrong. As the United Nations have stated any person or group victim of a violation of the right to health should have access to effective judicial or other appropriate remedies at both national and international level. In commented further it has been stated that the right to an effective remedy need not be interpreted as always requiring a judicial remedy and that administrative remedies will in many cases be adequate. Any such administrative remedies should be accessible, affordable, timely and effective.

In Northern Ireland the first avenue to redress issues regarding the right to health is often the health and Social Services Complaints System. The Department of Health, Social Services and Public safety launched a consultation in November 2006 on the current complaints system and proposed significant changes to the complaints structure in Northern Ireland. The consultation period ran until the end of March 2007 and as yet the findings of the consultation have not been released to those who responded

In the current complaints procedure, records are taken about what complaints are about, but not about action that was taken to improve services as a result of them. There is no requirement for Staff from the Board or hospitals to meet with the complainant to discuss their experience. In 2004/5 150 requests were made for access to Independent Review, the second stage of the complaints process, 42 of which in the Eastern Health and Social Service Board area. Only 9 of the requests were granted, 4 of which were in the Eastern Board area. Also concerning is the waiting time for a complaint to be dealt with by the Ombudsman. According to the Ombudsman's Annual Report the average time, in 2005-2006, taken for a health service case to be examined, enquiries made and a full Report issued at Report Stage was 101 weeks.

The new Complaints process proposals place a duty on health and social service organisations to publicise their complaints procedures and promote access to them, considering availability of publicity material and new mechanisms e.g. electronically and to advertise the support mechanisms that are in place to guide complainants through the process. The proposals also emphasise the importance of complaints being viewed as an opportunity to improve services. Ensuring greater transparency will go some way to ensure greater accountability in the protection and promotion of an individual's right to the highest attainable standard of mental health. However, of concern is the fact that the proposed new system offers little comment on monitoring arrangements. A best practice complaints system in Northern Ireland should be timely, independent, transparent, and accessible to the wider population. An effective complaints system should also have clear review mechanisms in place and provide access to independent advocacy services to assist complainants in the complaints process.

Implementation

I have made various references this morning to the process of implementing some of the main mental health policies. The implementation of mental health policies is key and that is often where we in Northern Ireland are suffering. The value of consultations, inquiries, reviews and strategies is at the end of the day controlled by the ability to implement the results or recommendations. As the Suicide Strategy states “One of the clearest messages coming from the consultation process was the need for action and not merely words in relation to the implementation of this strategy”

While each of the main areas I have spoken has taken steps to work towards implementation there is still considerable work to be done. The setting up of the Mental Health and Learning Disability Board is a significant step forward and the Suicide Strategy Implementation Body and the Five Nations Working Group alongside pressure from the Health Committee should ensure that suicide prevention and related policies are given proper consideration.

Disappointingly however, in the draft Programme for Government mental health was given only a brief mention in a commitment that by 2013 anyone with a mental health problem or learning disability is promptly and suitably treated in the community and no-one remains unnecessarily in hospital. This was a disappointing result coming after the high profile given to mental health as a result of the Bamford Review and Suicide Strategy. Further, despite a bid for mental health monies totalling 84 million, the draft budget has allocated a total of only 29 million over the next three years. This is a rise in funding of less than 1%.

In stark comparison from 2000-2006 the British Government have invested an average 6.6% per annum rise in mental health with 11.8% of the NHS budget allocated to mental health. In Northern Ireland despite a higher prevalence of mental health issues only 8.4% of the NHS budget is allocated to mental health. There are clear inequalities within the UK therefore in relation to the resourcing available for mental health services.

One of the other major concerns with implementation of any mental health policy in Northern Ireland is the lack of a qualified and adequate mental health workforce. Without an appropriate workforce many of the desired policies cannot be implemented. Again the draft budget comes up short with an allocation of 90 additional mental health staff for Northern Ireland in the first two years. Broken down to Trust level this equates to 18 new staff across all areas. When one considers that Bamford identified 10 distinct areas within the mental health field all requiring additional staff this means that each area has an allocation of less than 2 new staff members over 2 years which is unrealistic and unsustainable.

The United Nations standards on the right to health state that inappropriate resource allocation for mental health can in and of itself evidence discrimination.

Equality Concerns

As already mentioned there is clear inequality in the allocation of resources within the UK to implement mental health policies. Equality issues are vital to the promotion and development of mental health policies.

Unique to Northern Ireland under Section 75 of the Northern Ireland Act, public authorities including the Department of Health are under an obligation to pay due regard to promoting equality of opportunity in all their functions among those of different age, religious belief, political opinion, racial group, marital status or sexual orientation, and also between men and women, persons with a disability and persons without, and persons with dependents and persons without.

Among the requirements under Section 75 is the obligation for public authorities to carry out equality impact assessments to gauge the effect of their policies on the affected groups. It is of concern that neither the Suicide Strategy nor its predecessor Promoting Mental Health underwent a full equality impact assessment.

Preliminary research done before the suicide strategy identified a number of factors that increased the likelihood of requiring mental health services. For example, the high level of male suicide was noted, as was the prevalence of suicide among single people. Despite these findings, the Protect Life Strategy was deemed unlikely to have a significant impact on equality of opportunity.

The purpose of an equality impact assessment is about assessing how best to get at need effecting different groups. There is a need to target the inequalities identified between groups and use the assessment to find ways of improving things for the groups most in need. It is also essential that monitoring of effects of the policy on each of the groups is carried out in order to ascertain the impact of the policy in addressing the different needs of groups.

This is backed up by human rights standards under which States and governments have a positive obligation to ensure equality of opportunity for the enjoyment of the right to mental health services. This obligation demands special measures for particular groups.

Conclusion

Mental wellbeing underpins all aspects of health and wellbeing and promoting positive mental health and the prevention of mental ill health is a priority for the entire community. Central to the success of mental health improvement is recognition at all levels that mental health is everyone’s responsibility.

While it is clear that there is a level of commitment to improving services, policy and legislation for those with mental health issues in Northern Ireland. Mental health policies in Northern Ireland are lacking in effective monitoring systems, many are missing vital opportunities for participation within communities and the implementation of many policies fall at the resourcing hurdle.

Mental health policies must be developed to ensure participation at all levels, with clear arrangements for accountability and ongoing monitoring by all interested parties. Further policies must be implemented at all levels and by all parties to ensure success and on the ground change for those in need.

There are many challenges for all us to take on board but from what I’ve already heard this morning and what, no doubt, is to come this afternoon it is clear that there are many here today that are willing and able and keen to take on that challenge and we’ll do that together. So, thank you.

Inez McCormack: Thank you Laura. We've heard about the words of change. David Bamford with whom I was many, many years ago, a first year student did an extraordinary job to bring together the disparate policies, the disparate instruments and the disparate administrative functions in the north into a very concrete review of what could be done and how it could be done and what was necessary to be done.

I think we've heard in the DVDs this morning, in the voices this morning, of the lack of impact on the ground that that very clear, coherent view of how, with participation, with adequate resources and with targeted resource, how difference could be made in certain standards of right. What could actually happen.

You've heard from PIPS in terms of what the community response on the ground had been. Mitigating the need should be in the context of establishing the right to resources, not pushing against the wind.

I think, in a sense, Laura's contribution has made very clear that the language of participation, accountability and implementation is as good as the political will to actually support it being put into practice.

On the other hand, and there's always on the other hand, this can always remain absolutely mystifying and paralysing when it seems too much to do. I think what we heard this morning from individual voices and the collective voices is the sense that people say something can be done and we will do it.

The job of the PPR Project and the rights based approached is to set a context to enable the burden of proof to be in those who have the power and resource not in those who need it.

So, I'd now like to introduce Nicola to talk about the work that she and the project have been doing with PIPS and RAYS Groups to set baselines and indicators and to demystify that language as well.

Putting Human Rights into Action

Nicola Browne, PPR Project

Nicola Browne: Thank Inez. As Inez just said I'm going to talk a bit about the work with the PIPS/RAYS Rights Group that I've been doing. That work has been about putting rights into action and their campaign for better mental health services.

The groups have been working within the framework of the right to health. That's been recognised and committed to by both the UK and the Irish Government. The governments recognised the right of everybody to the highest attainable standard of health. That doesn't mean everybody has an absolute right to be healthy. What it does mean, for example, is that everyone has a right to social determinants of health, such as housing and education. But also, it means there's a human right to health services.

The standards elaborate on what health services need to look like. They said it has to be culturally acceptable, for example but, they also say, they have to be accessible – people have to be able to get to them and they have to be of good quality.

Under human rights law, government has an obligation to progressively realise the right to health. All that means is, year on year you need to be showing, that things are getting better and services are improving for people who are using them. This commitment that things are getting better year on year is going to be the one that the group measure throughout their work.

At the start of their work the group picked the issues they wanted to measure change on. Because what the group were doing was measuring change over time on a number of issues, they gathered evidence on what things are like now. That's their baseline. They have a baseline picture of what things are like for mental health service users now on these specific issues.

They then set human rights indicators to measure change on the issues. Indicators are basically measurements. So these are the things that the group are going to measure over the period of time to see if things are getting any better.

The value of the group's indicators is that mental health service users are actually measuring the benefits of money that's been put in by government. They are measuring the effectiveness of the policies and programmes that have been put in place that Laura talked about. So, they're charting the impact of those government polices and will determine if it's actually reaching the service users on the ground.

That's really the only place in terms of communities and on the ground that it can be judged if human rights are being taken from rhetoric and actually being made real.

The indicators the group have set have two purposes. For one thing, they'll measure change on the issue that they relate to. But, because the indicators are linked to human rights standards they also measure progress on the right. So, they'll measure how the government is doing in progressively realising the right to health, which they should be doing under human rights law.

So, in this way, the indicators they've chosen provide a crucial link between local experience on the ground and international human right's standards that have been accepted by governments.

The unique thing that the PIPS Rights Group have done in using a human rights based approach is they've set standards for change and they're the ones who have set benchmarks, who have set targets. These benchmarks or targets identify what progress on the right to health will look like for them as the affected group.

It’s vital that these are set by the affected group, in this case, mental health service users. That’s because the state, the government, the department of health isn’t a neutral actor. Under human rights law they’re the duty bearers. They owe an obligation to mental health service users to take positive action to realise these rights. So, it’s not the providers of services who should be defining what human rights progress looks like. It has to be the affected group and this is the group to whom government and its agencies owe the obligation to realise the right to health.

Also, the right to health includes the right of affected group to participate in decisions about their health services. That involves things like planning services, implementing them and evaluating them. It’s important to say that under human rights law this goes further than consultation. Consultation is often about having your view heard and often, that’s where it stops. Participation is about being involved in shaping decisions and influencing the outcomes.

So, this the work the PIPS/RAYS Rights Group are embarking on and that’s what we’re going to hear about next.

Thank you.

Setting the Standards and Measuring Change

Follow Up Appointments

Roberta Coates, PIPS/RAYS Rights Group

Inez McCormack: Okay folks, could everybody sit down, thank you.

Stephanie, who is one of the local development workers, is going to link the sections. We're going to have the presentation on the first issue, which has been selected by the groups which is follow-up appointments, Stephanie.

Stephanie Green: Thank you Inez. As Nicola mentioned the group collected evidence on their selected issues to get a picture of what people's experiences are of services now. We will now hear some of that evidence from the DVD and then Roberta will present the findings from the surveys on follow-up appointments.

So, we'll have the first clip from the DVD.

DVD evidence on Follow up appointments available on 'Rights in Action: Changing Mental Health Services' DVD

Roberta Coates: Hello my name is Roberta Coates and I work as the Crisis Co-ordinator for RAYS on the Woodvale Road. RAYS was set up in response to the increasing need for support services to people bereaved by suicide, people in crisis and to raise awareness on the issue of suicide and self-harm. Also, to reduce the stigma and isolation that accompanies bereaved families, people with mental health problems and those who self-harm.

Recent statistics would indicate a significant increase in the numbers of people presenting at Accident and Emergencies though self-harm. We know from our experience at RAYS that this is not the full picture as many of our clients would tell us that they haven't even been to A&E and that they were managing this themselves. This sends a worrying message of a growing trend, which seems to be affecting a high proportion of the population. Strategic and extensive research, we feel, needs to be undertaken across the province to identify the common features and causal factors associated with self-harm. So the targeted and responsive programmes can be put in place to effectively support people as they go through this time or turmoil.

When the two groups came together last October we soon realised that we shared common experiences of inadequate service provision for people with mental health problems and for people in crisis. Services were commonly inappropriate, inadequate and some instances, absent altogether.

For some, sadly, these realizations came too late and the devastation of suicide has featured in the lives of many who are here today. I thank those families who have come along today. They inspire me on a daily basis. So thank you for that.

Through the failures of this inadequate service provision for mental health care, collectively, we have agreed for the countless others that will, no doubt, follow behind us with their own experiences that we must do something now to challenge everyone's right to adequate treatment, care and support when faced with mental health problems and in crisis.

If we are to effectively raise the communities expectation to be able to work collectively in reducing the numbers of suicides and self-harm; and if we are to bring about hope for families and people in crisis; and if we're to reduce the stigma associated with mental health problems, we must be able access adequate, appropriate and timely services in a responsive manner which will meet the needs of service users comprehensively. Nothing more and nothing less will suffice.

The changes we are campaigning for may seem very simplistic in some cases yet, to patients, carers and family members they represent a measurable, transferable and tangible effect and being a life-line connection to individuals and family members when faced with great distress, despair and the struggles with coping with mental health and those in crisis.

We have a particular focus and vested interest today on the issue to ensure that if, and when, things do go wrong that we have clear pathways on how to access health and an assurance that the provision of adequate support care and follow-up services are there for us. That all can be done that has been done – not 'what if'.

Over the past year we have been monitoring change on the chosen issues that have been important to us. So, the first thing we did was to find out what things are like now on the specific issues we had chosen. This is called our baseline.

To find out the group designed a survey and we held a number of focus groups. We assessed 57 mental health users, mostly from North Belfast, as this is where the PIPS and RAYS projects are located. We were able to gather evidence based on the experiences of these mental health service users who are a very hard to reach group.

We then set benchmarks for change to measure whether people's experiences using mental health services were improving. Also, so we could measure whether our right to health was being fully realised.

Right now a lot of attention is being paid to mental health issues. A lot of policies are being put in place. Policies are fine but unless they're transferable they really mean nothing. A number of government committees have been set up which many of us find confusing.

What we found different about the approach of using human rights is that we as people on the ground who are most affected by the issues are setting the agenda about what this change is, how it will look and when it should change.

The first thing that we identified was getting a follow-up appointment when you're discharged from hospital. We felt that this was something that we could possibly get quick and effective change on and that it wouldn't require many resources.

The Mater Hospital has issued guidance and follow-up procedures and its discharge protocols since February of this year. In that it states: while the time of follow-up is an issue to be decided by local clinicians, they should be aware of the national guidance. National guidance states that all discharged patients who have severe mental health illness or a recent history of deliberate self-harm should be followed-up within one week.

If you look at our first slide according to our survey 13% of those discharged from hospital after mental health treatment had received a follow-up appointment within a week. The vast majority had received their treatment at the Mater Hospital.

This issue is about accessing health services. Under human rights law health services have to be accessible to everyone without discrimination, especially the most vulnerable and marginalised sections of the population. The right to health includes the provision of equal and timely access to appropriate mental health treatment, care, services, support and follow-up systems.

Over the next year we want to measure what progress the Department of Health is making to meet this need. We will measure the number of patients discharged from hospital after mental health treatment who receive their follow-up appointment within a week. This is a small issue but one that will make a huge difference to families and at local level on the ground if it was addressed. As a result the group, as you can imagine, is keen to see it happen quickly.

The next slide sets out our timetable for change. In six months they want an increase to 45% of people receiving a follow-up appointment within a week. Within a year the group would like to see a system in place ensuring that 90% receive their follow-up within a week.

The group thinks the issue of follow-up appointment should be addressed as a matter of priority in order to show progress in working towards the fulfilment of the right to health.

Thank you.

Inez McCormack: Thank you very much.

I'm just going to ask the panel to give a bit of feedback because this is now the link between the international and the global. This is actually the words and the action – how, in fact, can people on the ground take the work that they're doing and set it in the context of right and get it realised. So, if I could just go this way this time, Camilla?

Camilla Parker: I think my comments perhaps will be more general than my colleagues. Roberta, you mentioned that some of the points you made are simplistic in some cases, but actually, I think that's the beauty of this indicator, in that it's very clear. It has been stressed by a number of you that it has very limited resource implications because it seems that this is meant to be happening in any event. So, I think, as I said, that its beauty is in the simplicity. I think it's very clear from the evidence you put forward that it could have an enormous impact upon service users. I think that's a really important point.

I just wondered about this point about national guidance and what happens in practice. It seems that the hospitals or the psychiatrists can look at the national guidance and its then up to them to decide whether they're going to follow that. I just wondered whether there were any opportunities of having a discussion with the management of the hospital about making sure that that is not just simply guidance that people can follow if they so wish. But, that it's something the hospital would then take on board as a quality assurance, if you like, to say, 'this is something we've signed up to. Its national guidance but we're going to ensure that this is complied with.' Perhaps also looking at why that isn't complied with in the cases it's not. It's just a suggestion.

Inez McCormack: Thank you.

Tara Melish: I'll just make another couple of comments much in the same line. I think that this indicator is such an appropriate and important indicator to have chosen. I know that you came up with a long list of possibilities and you prioritised them with the things that really could make a difference in the short term that were easy.

This is a very clear example of an indicator with benchmarks that are entirely reasonable and will not be difficult to achieve within the six-month period and the one-year period. So it's an excellent choice of an indicator, particularly starting out in this process and starting the relationship working with the Health Ministries around achieving benchmarks through performance monitoring.

I think it's important to recognise that it will take a good deal of action on the part of the health authority. We should be very clear on what sorts of actions would be appropriate to take and work with those authorities because that's really where the knowledge of the users and the community is. Not only in identifying where the problem areas are but identifying solutions.

Along the lines that Camilla just mentioned, in looking at the guidance, one possible approach that jumps out in a certain way is that in the Mater Hospital we have the guidance, while the timing of follow-up is an issue to be decided by local clinicians, they should be aware of national guidance. You may try to work with the authorities at the Mater Hospital to add to that, specifically, the national guidance but changing the ‘should’ to ‘must’. So, just add in the national guidance. So, after what is currently in the Mater Hospital guidance, say, ‘all discharged patients who have severe mental illness or a recent history of deliberate self-harm must be followed-up within one week.’ Include that in writing so that there is some sort of an accountability mechanism within the Hospital structure itself.

It’s important that there are consequences for service providers who aren’t providing a follow-up within in one week. It’s really outrageous the fact that only 13% of users are receiving that follow-up care. So that might be one particular strategy to use with local authorities around using this benchmarking and performance monitoring on the strategy which is so important.

The other thing that I’ll just mention quickly is that you mentioned here accessibility, the UN Committee on Economic, Social and Cultural Rights, in its General Comment, Number 14, mentions that there are ‘four elements to the right to the highest attainable standard of physical and mental health which includes, availability, accessibility, acceptability and quality.’

Here we’ve mentioned the important element of accessibility we also have the critical element of the availability of follow-up services. But, we might talk specifically with our authorities about ensuring the quality. So, we’re not just having a follow-up appointment and that our benchmark is not just monitoring, ‘is there a follow-up appointment’, without actually looking at the quality of the follow-up that’s provided. So, that might be another way to engage with the system through this important process.

Inez McCormack: Thank you. Christian.

Christian Courtis: A couple of comments of different levels. The first one is more generalist. The fact that this methodology is not only focused on the specific issue of suicide rates regarding mental health services. It’s a very interesting methodology, in general, for other issues regarding mental health services, other issues regarding health services in general, physical health – not only mental health. It can also be used beyond the area of health, for example, in housing or education.

In the human rights perspective it’s very important to underscore the voice of users of services as monitoring services and the notion that indicators and benchmarks are a way of assessing this progressive realisation of rights can be replicated in other areas. So, this is completely in line with some of the exigencies that come from international law. I would underscore this as a best practice only taking one particular issue.

A number of other things I’ll go in line with what has been said before. One, choosing this particular indicator I think is important in terms of seeing the link between in-patient services and the services that are delivered in the community. A number of international instruments underscore the importance of people being treated in the community and the right to be included in the community as a principal.

That doesn't mean that there should be no in-patient treatment. But, the crucial fact here is how both services are linked. So, what you're trying to underscore is the quality of the way in which in-patient treatment gets follow-up when the person is back in the community.

That brings up the issue of quality – how to assess quality. A service that is delivered in an in-patient setting that doesn't have follow-up is actually money which is badly used because you use bed time, you use time for professional staff that then doesn't have follow-up so that money was badly delivered.

This is a very important way in order to link the way you use limited resources in in-patient services as you follow-up in the community what happens with persons that have received service. This looks as a very important indicator of the quality of services and it may also have some other outcomes regarding the accessibility and also the availability of services. So, well done.

Inez McCormack: Thank you very much.

I think also in the sense of what we've heard from the feedback from the panel and we've heard from this first indicator that the important thing is that the local communities have taken the language of progressive realisation and they've taken the language of time and have set in something which is modest and reasonable. I just think the panellists are spot on. There's absolutely no reason why this should not be addressed.

If I'm right Gerard, I think that, in fact, there was after the review as a result of Danny's death, the sense was there was meant to be *changes to ensure people received their appointments*. That was a commitment given by the hospital, which was never actually followed through. So, in a sense I think the language from 'may' to 'must', I think it was campaigners around human rights who have spent their lives trying to go from 'may' to 'must'. But, the 'may' to 'must', I think, is going to be fairly crucial in our work in the next six to twelve months.

So, can I thank the panel very much for their feedback? Can we move on to the next speaker Stephanie?

Setting the Standards and Measuring Change

Information from GPs

Jean Hand, PIPS/RAYS Rights Group

Stephanie Green: Thank you for that input. The second issue that was selected was information from GPs. After the DVD clip on this, Jean will present the survey findings. So first of all we'll just see the DVD clip.

DVD evidence on Information from GPs is available on the 'Rights in Action; Changing Mental Health Services' DVD

Jean Hand: Hello, my name is Jean Hand and I'm a member of PIPS. I lost my daughter two years ago in October to suicide. She didn't present with any mental health problems that we knew of and at the time we just wished she had come and told us and that we could have got her help. But, with being in the PIPS group I realised that if she had gotten that help, although we have a very good GP, beyond that it might have been very difficult and the outcome may have been the same and that's why involved with this project.

Most members of the PIPS/RAYS Rights Group, and many others, have had poor experiences of attending a GP with a mental health problem. The group felt that the GP was often the first port of call for those suffering mental health problems. The experience here is crucial to accessing the right care.

When the Promoting Mental Health Strategy was launched in 2003, it aimed to ensure GPs were trained in depression awareness. GP training in Depression Awareness was to be rolled out by 2004, but this did not happen. The Suicide Strategy also says that educating GPs about depression has shown promising results in preventing suicide. The training is now taking place– it takes only three hours and locum cover is provided. But uptake has been low – only 218 GPs in Northern Ireland have been trained so far. In the Eastern Board Area, which includes North and West Belfast, only 14% of GPs have taken the training.

The United Nations has stated that the right to health includes access to health related education and information.

We are aware that the GP Depression Awareness training is ongoing and is a priority in the suicide strategy. Therefore over the next year we will monitor the following human rights indicators to see if this right is being made real.

Firstly, the number of people satisfied with information from their GPs on mental health problems. As you can see from the slide, our baseline found that 36% were satisfied. In six months this should be increased to 50% satisfied. In a year this should be increased to 70% satisfied with information from GPs on mental health problems.

Secondly, we will monitor the number of people reporting satisfaction with information from GPs specifically on medication prescribed for mental health.

This issue came up again and again in our focus groups – as we heard stories about the easy availability of anti-depressants – but that people weren't getting enough information on what was prescribed.

The United Nations has stated that the right to health includes an obligation to support people in making informed choices about their health.

As you can see from our slide – currently 38% are satisfied with information from GPs on medication for mental health conditions. In six months the group wants to see an increase to 50% satisfied.

In a year the group wants to see an increase to 70% satisfied with information.

Thank you.

Inez McCormack: Thank you very much Jean. Again, I'd like to ask the panel for some feedback and I'm going to start at that end this time. So Christian will start.

Christian Courtis: First, one of the elements of the right to health is accessibility and access to information is a key element. Then, access to information in this particular case is a key element because it touches on the way in which primary health care is delivered so it has a preventative effect that then is cost effective in terms of what you prevent from happening in the future. So, again, this is a very intelligent way of pinpointing the subject.

What I would like to say as a supplement is that mental health services have been the black sheep and the poor brother of the family of health services. There's a number of instruments in the international sphere that underscore the need for equality in the access to mental health services in comparison to other health services.

This is a way of mainstreaming the notion of the access to mental health services in the way in which primary health care is given. Again, it's another intelligent way of using existing resources because of the way in which access to primary care is structured goes through GPs. Mainstreaming in that particular scenario, the basic notions about access to mental health. So, I would say that this complies with the idea that relevant information should be provided as a way of levelling the place mental health needs are given in the health care service. Thanks.

Inez McCormack: Thank you Christian. Tara?

Tara Melish: Thank you and thank you Jean. I just wanted to start by reaffirming the absolute imperative of receiving appropriate information from health care providers on the conditions that they treat and the medications that they provide. Not only from the perspective of prevention and from personal integrity but also, medical ethics, personal autonomy, in the sense of the right to free and informed consent to any medical treatments that one receives.

Within this context, I'd like to mention just three points, or maybe two points and a question that might be posed that we can discuss either now or at a later time.

First, I just wanted to express alarm at the fact that so few of the GPs have been trained thus far. I think you mentioned only 14% and this training has been called a priority, the training has been recognised for its role in preventing suicide and still even thought this policy has been unfolded, there is still only 14% of GPs trained. That means the government is doing something wrong. It's not taking appropriate measures to ensure that GPs are, in fact, undertaking this training.

In that sense, I'm glad that you're also monitoring the quantitative indicator of how many GPs are, in fact, being trained. That is important to always monitor and to be used in your strategies with local government.

Second, it's important to affirm that you have picked a very good indicator because just measuring the number of people who have received the training doesn't really say anything about how effectively their communicating that information to users. So, measuring the satisfaction with the information provided is absolutely crucial and is so important for this project. That is, we need to measure both the quantitative indicators and those qualitative signs of progress, ‘how well are we doing?’

The third thing that I wanted to really ask was whether in the process of undertaking the surveys and working with focus groups there was a focus on why people were dissatisfied. Because that goes to the question of whether the trainings actually respond to all of the obstacles that are identified by people and the reasons why they’re dissatisfied with the information that they are being provided by practitioners. So, that’s an important point to be able to be able to bring up with health authorities – is the training enough or are there aspects that need to be added to the training in order to respond to the problems that have been identified by users.

Inez McCormack: Thank you. Camilla.

Camilla Parker: Thank you. I think I’ll pick up on the last point that Tara made in relation to the training. Like Tara I’m very concerned about the low uptake but there may be issues around the training. I just wondered whether there may be some opportunities of talking to those who are organizing the training to find out what the training is and whether people who use mental health services might be able to participate in the training because that might be an effective way of getting the message across to the GPs.

It occurred to me when listening to the DVD and Jean that we are looking at a serious problem here. I think it’s about inequality of access in relation to mental health. Mental health problems should be treated in the same way as any physical health problems but clearly this is not the case.

There’s still a lack of interest, it would seem, from the figures that have been given about the number of GPs taking the training, which, therefore, means that there’s a lack of awareness around mental health issues. That then means that, as your indicators show, there is dissatisfaction with the information that GPs are providing.

So, I think there are a number of routes to push this issue up the various agendas in terms of getting GPs training, and highlighting to the authorities the impact of that lack of awareness amongst GPs.

I just want to also talk about the information in relation to medication and I’m really so pleased that that’s something you’re looking at because clearly it is a huge issue. Again, taking up on my colleagues’ points about inform and consent. That does have a direct relevance to human rights. When we are talking about inform and consent what should be happening is that you should have the GP talking about the medication that he or she is proposing, explaining why he or she is proposing that, what condition it’s meant to be directed towards. But also, talking about the potential side effects and I think that was something that came very clearly from the DVD, that lack of understanding of what the potential side effects may be. Very sadly, many of the medications for mental health problems do have very difficult side effects. I think it’s important for the person to know that and to be able to think through some of the issues in order to decide whether he or she wants to receive the medication and what the alternatives are.

That’s something else that GPs should be discussing. I don’t know whether that’s something that could be brought into that indicator but I think both of them are crucially important.

Again, thank you very much for some very crucial indicators there.

Inez McCormack: Thank you very much Camilla. I’m going to introduce Gerard. Again the same point, if I remember rightly and I look at the groups to correct me, or Stephanie. I think when, in fact, those figures came out about the number of GPs who have not undertaken any kind of training, I think one of the defence mechanisms used by the representatives of the GPs was to say that, in fact, the training itself was of very little use to them because they had done it already. Well, it kind of begs the question, if they had done it already then why wasn't it effective and useful?

But, I think again as an example of how, in fact, change is perfectly possible if the behaviour of the medical profession and the behaviour of the political controllers and the behaviour of the Administration came together and got the service users in the room – this is perfectly possible to do. So, again, I think what we've got is, and I think this is, pardon me to use the language, a health warning, in a sense.

We have a twelve-month indicator with very reasonable timetables and yet this should have been so easily done.

So, can we ask Stephanie to introduce the next indicator?

Setting the Standards and Measuring Change

Complaints

Gerard McCartan, PIPS/RAYS Rights Group

Stephanie Green: The next issue that the group chose was complaints. Gerard will be speaking on that in a minute just after we see the clip from the DVD.

DVD evidence on complaints is included on 'Rights in Action: Changing Mental Health Services' DVD

Gerard McCartan: The next issue we identified was that of complaints. The group was first interested in the complaints system because it seems like the obvious place to turn when something goes wrong with your treatment. We found that there were a lot of issues about making complaints – including knowing you could make a complaint, knowing how to do it and getting a satisfactory outcome.

We thought the most important issue was people's inability to access the complaints system when dissatisfied with mental health services. In our baseline survey we found that 69% of mental health services users dissatisfied with their treatment did not access the complaints system. Half of those who didn't use complaints procedures said that they didn't know how to. 40% said they didn't think it would make a difference to complain. The rest said that because of their distress at the time, they were in no fit state to complain.

Complaints are important because they are about making sure lessons are learned. But first we need to make sure people even know there is something they can do when things go wrong. The fact that many people do not know how to go about making a complaint, and that many have little faith that it would make any difference, needs to be taken on board in the new procedures being drawn up.

The current complaints system is being reviewed. The new proposals state:

"Service users should be made aware of their right to complain and given the opportunity to understand all possible options for pursuing a complaint. Complainants must, where appropriate, have the support they need to articulate their concerns and successfully navigate the system"

The UN also said that administrative remedies, such as the complaints system, should be:

"accessible, timely and effective"

Over the next year we want to measure what progress the Department of Health is making to realize this right. Over the next year we are going to measure the following indicators. The first one is the number of dissatisfied mental health service users accessing the complaints system.

We know that not everyone will want to make a complaint. However the group believes that improvement on this indicator will show that the underlying problems of people not knowing how to complain, and thinking that it won't make any difference, are being addressed.

The UN has stated that:

"Any person or group who is a victim of a violation of the right to health should have access to effective remedies"

The group wants to see the number of dissatisfied mental health service users accessing the complaints system reaching 45% in six months and 55% in a year.

We are also going to measure the number of those who are offered help to make a complaint. Of those who did use the complaints system, which was a much smaller number of those we surveyed, only 18% were offered help to do so. We know that changes are currently taking place in the complaints system to ensure that people get help when making a complaint. As a result we think it is fair to expect a significant improvement in the number of people offered help.

In six months the group wants to see the number of people offered help at 50% and within a year it should be 80%.

An effective complaints process will make sure that lessons are learned when things go wrong. Progress on this issue will indicate whether our right to an effective remedy is being realized. Thank you.

Inez McCormack: Thank you very much Gerard. Again I'm going to ask the panel for some feedback. May I start with Tara this time?

Tara Melish: Thank you Gerard. I want to just underscore one of the really important things that you said which is, 'complaints are important because they are about making sure lessons are learnt'. That's so important to underscore because as we saw in the DVD those who complain are often thought of as troublemakers. It's necessary that we change that thinking around.

Those who complain are assisting the government in its obligation of progressively realising the right to health. They are showing the flaws in order that they are corrected and that we can move forward. Therefore, the only way that we do progress is by recognising things that we are doing wrong, weaknesses. So that we can correct them and then move forward. So, we need to rethink what complaints are and see them as something positive, constructive and something that we need to embrace.

That is where the knowledge base that we have at the local level – that's why it's so important. That is why participation is so important. We can only, again this has been repeated by many of the speakers, achieve the right to health if everybody is involved. Not only the government but all of civil society, the private sector and the media. That involves all of us coming forward where we see problems or we have potential solutions to offer those up so that we can move forward as a collective.

So, I'll stop there.

Inez McCormack: Christian?

Christian Courtis: A number of things. One has to do with previous comments. You have picked an outcome indicator around the performance of the complaints system in terms of accessing it. But, that begs the questions of what is the quality of complaints that are placed there? So this outcome indicator would lead to the question of are the existing complaint mechanisms adequate or inadequate? And, there may be different solutions. You may come to the conclusion that they are adequate but there's a lack of information about how to access them. Or, the answer could be, they are inadequate because they lack a number of substantive elements required in order to define this notion of an effective remedy. So, just some ideas about what are effective remedies. One has to do with access to the remedy. So information about the remedy – assistance regarding the possibility of exercising this right.

There's another component that has to do with who the authority is that has the task of reviewing the decision. So, a notion that a remedy is only a remedy if the authority that reviews the situation is impartial and independent. If you file a complaint to the same authorities that took the decision I can bet that the decision would be always upheld. The notion is that a correct mechanism for complaints should have the hallmarks of impartiality and independence.

The third element is how effective the remedy or the answer that is given by the complaint system is in relation to the grievance. If the complaint ends up in a report with no effect or with a recommendation or resolution that is not mandatory – what would be the effectiveness of going through this Kafkian process of complaining?

There are some elements that build up the notion of a remedy or of a complaint as an effective remedy and I think those should be taken into consideration as measures of what an effective remedy is – reviewing what are the mechanisms in place there.

Lastly, I think there is a strong link between a complaints mechanism and participation. Sometimes they are seen as contradictory. The persons that complain are troublemakers and persons that participate are seen with a more sympathetic view. But, one of the ways of showing the failures of the system is through complaints. So the aggregation of different complaints is a great way of showing which are the shortcomings of a system. So, it's one of the possible channels for participation. So, I would underscore that both of them are intertwined in an important way. Thank you.

Inez McCormack: Thank you very much. Camilla.

Camilla Parker: I just wanted to pick up on points that both Christian and Tara made. The first one is really about the lessons learned and Tara was talking about people who make complaints being seen to be troublemakers. Whereas, in fact, they're doing the service a favour and that's really how complaints should be looked at. Often you hear that in theory, that's what people say but it should really be something that people working in services, and in this case we're talking about mental health services, really do value those people who can take the time and the trouble to make a complaint. Because it actually does take a lot of time, and sadly, it does often take a lot of trouble. That's something that does need to be addressed. It really can be used as an effective means of improving services and it should be seen in that way by those who are delivering the services.

So, I would hope that this indicator can be used not just at the Department of Health but also to try and get hospitals to really embrace this as something that is valuable to them. They're being given something that they can use that can make a difference. So that they can be very proud in saying, actually we deliver a good service and we welcome complaints because we see this as a mechanism for us to identify problems and try to address them.

I just wanted to talk just very briefly, if I may, about some experience I've had in London. I was for about five years on the Board of Mental Health Trust and there was a committee that looked at, amongst other things, summaries of all complaints that the Trust received. On that committee there were two people who had experience of using mental health services. The committee had the Medical Director, the Nursing Director and others.

So we were all around the table looking at the summaries of complaints. We had some very important and interesting discussions around the findings of the complaints. Quite often we would be talking about the process of the complaint system and whether that was something that was difficult for people to make the complaint. But, it was also about – okay, here's a compliant, what are we going to do about it?

I just wondered whether that might be, I know this is moving on a bit further from the indictors, but that there are ways of really ensuring that complaints, as both Tara and Christian have been saying, form part of the participation process. There are ways of thinking about how can we use this complaint system to improve the services, which is in everybody's interest, those who are providing the services and, most particularly, those who are receiving them. And also for the families and friends who are supporting people with mental health services.

So, once again, I just really congratulate the group on identifying some indicators that I think can have real practical use. I'd love to come back in six to twelve months time to find out how you succeed because I'm sure you will have achieved a lot. Thank you.

Inez McCormack: Now wasn't that a foolish thing for her to say? You're invited!

I just think the point that Christian made is in fact that the complaints procedure was reviewed because it's actually recognised by all as fairly inadequate. It is actually a very technical, closed, administrative process, which has very little response to things and also does regard the person who's making the complaints as a problem. Also, the immediate response is to actually regard the fact as 'could this be subject to a legal challenge'? So, it's a complete defensive mechanism.

Camilla Parker: One of the points you're looking at is what help do people receive and I think Laura mentioned in terms of the review of the complaints procedures that there will be discussions around people having the right to an advocate. I would very much hope that that is an outcome of the consultation process because I think it is really vital that people do have independent, specialist advice to guide them through the complaints procedures. So, I think that would be something that would be really important to try and ensure as part of the new complaints system which hopefully will be introduced as soon as possible.

Inez McCormack: No, I think it's not an addendum – I think it is a very core point to someone who's spent a lifetime with people who are, on the whole, powerless. And, when they're in the room with power in the sense looking for the space to have someone with you – doesn't mean that you're not capable of making your case but, that you have somebody who needs to balance the relationship. In terms of both the information and the sense that there are accountabilities – is a very core point.

Setting the Standards and Measuring Change

Participation

Gerard McCartan PIPS/RAYS Rights Group

Stephanie Green: Okay. The final issue was participation, which the group chose. So, we'll have a quick look at that.

DVD evidence on Participation is available on 'Rights in Action: Changing Mental Health Services' DVD

Inez McCormack: Thank you very much. I mean this is probably one of the most crucial, core issues to make any for this work so Gerard, you're on again.

Gerard McCartan: This is the last! The final and most important indicator the group wants to measure is about participation. Many of the PIPS/RAYS Rights Group has been involved in committees or bodies who are working on improving mental health services. Many other mental health service users are not. Even when we are involved, our voices may be heard, but not properly listened to.

In our baseline survey, most people rated their level of participation as low. 79% rated their level of involvement as between 1-3 on a scale of 1-10.

The right to participate is part of the right to the highest attainable standard of health which the government has signed up to improve year on year. The UN has stated that this means more than merely being consulted – participation must be active, free and meaningful. In practice this should mean the voices of mental health service users are sought out. Information they receive should be clear, without jargon, and given to the groups in plenty of time to allow them to contribute to decisions.

In six months the group thinks that the 79% who rate themselves as not involved, should be reduced to 65%. In a year it should move to 50%.

Participation in decision-making is not only part of the human right to health. If realized, it would lead to better and more effective policies and procedures for all.

Thank you

Inez McCormack: I know we're running near lunch but I think, if you forgive me, I'm going to ask the panel to give some feedback on this because it's core to all of our work.

Can I start with Christian?

Christian Courtis: Along the same line of the previous comments – what you have identified are outcome indicators –the satisfaction of the involvement of users and families in the services. Again, that begs the question about which are the formal channels for participation? Are they adequate or not? An answer on this could be because the channels are inadequate people feel that they have no place to participate and they don't get involved. So one question is to review how participation is enshrined in formal mechanisms in order to have the voices of users and families in the process of decision-making and evaluation?

There are a number of possibilities. One is, are there public hearings before the adoption of measures that would affect the services? Is there a participatory process to receive comments on a proposed protocol or policy that is put in place? Is there any formal way to receive proposals about things to be included in policies, protocols, norms that then would be the basis for the application of possible policy? What is the role of users and family groups on boards or other advisory bodies that would have some say in the adoption of some policies? Is there any consultation process that respects the right to receive information before the consultation is being made? Is there enough publicity? How is it channelled through the possible users?

Sometimes you have these consultations that actually happen underground without any publicity. So, the box is ticked because a little advertisement is published in some official register but no one knew about it. So someone can say, ‘we complied with this box ticking’. So, we need to ensure that a mechanism is in place in order to ensure real participation.

Also, reviewing what the formal mechanisms are and how they are put in place is very important. That would be the next step in order to see ‘where’ and ‘how’ you want to participate in services.

Thanks.

Tara Melish: Yes, I too just want to underscore the importance of the effectiveness of the mechanisms that we create in our society for participation. We all have lots of policies that purport to be participatory. Such as, consultations in many of our countries, and I think here as well. There are consultations associated with virtually all legislation that is passed but, as we said, people don’t know about them or people spend lots of time writing out their views on legislation and there is no guarantee or process, you don’t know if it has actually been taken into account. It’s sent off somewhere and it may not actually be read by anybody. Or, you have circumstances such as boards that are created to ensure participation and then they aren’t actually involved in core decisions that are made by that group.

So, there are lots of ways that we say we are participatory and this is another area where we need to have complaints coming in – where we see deficiencies in the mechanisms that we create. Are they, in fact, participatory? Is this a way in which our voices can actually be heard?

Two points related to this that I’d like to raise. One is just to mention another resource that we have internationally. We had mentioned the recent adoption of the UN Convention on the Rights of Persons with Disabilities and there are two core articles in that Convention that relate directly to the need, the imperative, of the participation of persons with disabilities and their representative organisations. One is laid out in the General Obligations that apply. And, I should mention that the UK signed the Convention on the Rights of Persons with Disabilities on its opening day, along with 87 other states. It has yet to ratify but signature denotes an intent to ratify at a later time and there was a good deal of support from the UK in the negotiation process.

But, I’ll just mention those two Articles so that we can use them as a resource. Article 4.3 is a General Obligation, which applies to all of the substantive provisions in the Convention, including the provision on the right to health and the right to mental health, in particular. It says: In the development and implementation of legislation of policies to implement the present Convention and in other decision making processes concerning issues related to persons with disabilities, states parties shall closely consult with and actively involve persons with disabilities through their representative organisations.

There is also Article 33.3, which relates to national level implementation and the monitoring of government obligations under the Convention. It says specifically that, civil society and, in particular, persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process. And, in this regard I should point out again that consultation does not necessarily signify participation. That's something that Gerard has mentioned and that we see in definitions of participation around the world.

The World Bank, for example, defines participation that is, the process through which stakeholders and those who are affected by the outcome of reform or capable of affecting the reform influence or share control over setting priorities, making policy, allocating resources, and ensuring access to public goods and services.

So, these are some of the tools that we can use. I will just mention quickly, I know we're running out of time but, I think in terms of comparative perspectives, there are a number of initiatives happening around the world where people are looking to try to find new ways to participate because they're finding themselves in the same situation of not having a voice even in institutions that purport to be open to their voices.

We've been seeing national hearings around the right to health and other core economic and social rights issues in South Africa, for example and very recently in the United States. So, maybe in closing remarks I'll mention those because I think that they are good learning experiences. There is so much that we learn from what is happening here and what is important is how we can bring those two experiences together. What works and what might not work so well.

Inez McCormack: Thank you very much.

Camilla Parker: I'll keep it short because I suspect people are getting quite hungry. I think really from what's been said it's clear that, yes, participation is the most important indicator that you've identified. But, I think it's the most challenging if it's going to be done properly in a meaningful way. More needs to be done about how that can happen. I think the fact that you've raised it will hopefully mean that you can engage in those discussions because for me participation happens on a wide range of different levels. It's whether the person receiving the individual care is involved in his or her care planning to people using mental health services and their families and supporters having a say in how those services are being delivered. I think it's perhaps about how we can share information and exchange good ideas about how we can make that happen.

Very quickly, one aspect would be what's referred to as experts by experience. Tara mentioned monitoring and this is probably happening in Northern Ireland. There are bodies that go in to inspect services and they increasingly should be ensuring that people who have experience of using those services are part of the team that actually gives the view on the quality of services being delivered. So, that's one aspect of many that we need to look at in order to ensure that participation is actually something that 'a' is happening, but 'b' is happening in a way that people feel that their contribution is being valued and listened to and making a difference for the services that are being provided.

Inez McCormack: I think the ironic thing in Northern Ireland is that underpinning, if you like the definitions spelt out about the World Bank, is legislation passed in the Good Friday Agreement and then expressed in the Northern Ireland Act, Section 75, which is about the right to participate, the right to be involved in the shape design and implementation of policy which was mentioned earlier on by Nicola. That is all there, but in a sense all of this is as good as it is implemented.

But, in the last ten years since the Good Friday Agreement and the Northern Ireland Act we have seen also the complete unwillingness by administrative systems to implement it in a meaningful way because it is not about ticking a box. It's about listening to life experience and experience of service provision and altering service provision in a way that it is actually effective and responsive and flexible.

Again, none of that is about cost. All of that is about behaviour. So, in a sense, I think bringing in the question of the local rights together with the national rights.

If people have any written question or comments they'd like to make there are forms in your pack. If you could leave them either here or at the table outside. Could I also strongly say to the people who are putting in questions or comments we may not be able to deal with individual issues because this is an approach that can be used by anybody if we actually win the right. So, we'll try and take what we can but if there are any issues that we can't deal with because of time constraints or because they're specific issues, there will be a discussion and follow-up with people afterward.

Mental Health Services in Ireland – Comparative Perspectives

Nuala Smith

Youth Participation Officer, Headstrong

Sarah Hayden

Youth Advisory Panel, Headstrong

Inez McCormack: Welcome back all of you who have stayed. You're very welcome. I know many people have other commitments in the afternoon but thank you very much for staying.

As you can see from the timetable what we're going to do now is actually to have some of the experiences of some of the groups working in the Republic of Ireland.

So, first of all, we have Headstrong which is a member-based organisation in the Republic. I'm going to ask Nuala Smith, who is a Youth Participation Officer, to introduce Sarah who is going to give a presentation.

Nuala Smith: Hi everyone. I'm the Youth Participation Officer with Headstrong who are a new organisation. We've just been established over a year now and we are looking at establishing youth mental health services in the Republic of Ireland.

So, I'll just start a little bit by giving you the context for youth mental health and where we feel that we get our mandate. I suppose very similar to your experiences here. There are huge issues for mental health for young people in Ireland. The problem with the services in the Republic are similar to your experiences here. They're very poor at engaging young people. The main issues being that they're fragmented, they're inappropriate and they fail to address the specific needs of young people.

Headstrong is an independently funded NGO mainly through private donations. We aren't set up to provide direct services to young people. Instead we work out of a community development model to really support communities to wrap them around the young people themselves. And, to see where the expertise lies within the communities and to build on that. Also, then to work with relevant organisations and other stakeholders to start looking at providing services.

We're going to be running five pilots over the next three years and then after that time we're hoping to expand the Jigsaw Model nationally.

So, our vision is that young people are heard, respected and supported as they journey into adulthood. That's something that we feel very, very strongly about. We don't feel that it's possible for us to change or introduce a revolution to youth mental health services in Ireland unless young people are involved. So, our Youth Panel, which Sarah is a member of have been involved from the very beginning and have really supported the growth of Headstrong. They've been an excellent panel of people to pool from. I think what's been a real strength to us is their insight and their very practical solutions to some of the barriers that young people face to enter mental health services.

So, our programmes, this is kind of what they look like. We're going to have service development, research and advocacy. Service development is the pilot projects that we were talking about. That's going to be the Jigsaw Projects which will be a community-based initiative supporting communities to provide services to their young people.

Research will be a key element. To date we've done a huge amount of research into international best practice and international model that have really worked for young people. We've brought that learning to an Irish context.

Then advocacy which is probably the part our Youth Advisory Panel are most strongly engaged in. That's going to be a huge piece of work for us. Our long-term goal would be reducing the stigma around mental health services.

The idea of Jigsaw is about bringing the people in communities that care about young people together. It's not about having a model that's going to be a 'one model fits all' for every community. What it's about is designing bespoke services for young people in each community and by listening to local expertise, young people and their families, we hope that we can design services that will really engage with young people.

We also feel that we will very much focus on adding to and complimenting existing services rather than duplicating them. When we pick a site we go into a big piece of research with the community – looking at their needs, looking at existing efforts and looking at how we can fill gaps that might exist.

So, because we have a great amount of expertise in the organisation, we can bring international best practice. So, when we are looking at setting up service in a local area we bring that international best practice to the local context as well.

What we're hoping we'll be able to offer young people the support where they want it, when they want it and when they need it. The services that they will get will be welcoming, respectful and confidential. And young people will have a whole community behind them, supporting them. Using the adage that it takes a village to raise a child. We really strongly believe in that.

So, how it works is that young people will have a clear pathway into and out of services and that the front door service, which would be the first service that they enter, would be a very relaxed, easy place to access, a very youth-friendly environment.

Then, there would be a very clear and seamless pathway for a young person into general health information and support into generic counselling primary care and then into specialist mental health services if they need it. But also, instead of being stuck in specialist mental services there's a very clear pathway for them out. And, that each of these services would work together and support each other – that the young person doesn't find that they're just being passed from one person to another person when they're going into and out of services.

So, that's kind of a very brief introduction to Headstrong — the Speedy Gonzales version, because I'm conscious of trying to get you through it and get us out in time.

But, I'd like just to introduce Sarah now who, as I said, is a member of our Youth Advisory Panel. Our Youth Advisory Panel have been, as I said, really, really supportive of the development of Headstrong. We would really recommend, if you were looking at developing any youth mental health initiatives, that you would have young people involved. It's been just a huge asset to us. Also, Sarah has a huge amount of expertise and I think you're going to really enjoy listening to her. So, thank you very much for your time. Thank you.

Sarah Hayden: Hello. I'm delighted to have the opportunity to speak with you today in this capacity. Two months ago we were involved with Headstrong in helping out with a workshop for a training day for GP trainers – on how GPs should approach youth mental health. I suppose that the kind of exchange of information there really informed what I'm going to speak about today.

I was asked to speak on the four issues that we're addressing today and I suppose I'm just going to go through them myself but from a youth mental health perspective and very specifically, for young people rather than for all us, whether it's through association or directly.

I think that access to information is a crucial issue for any service user but perhaps particularly for young people. It's an area we're always drawn back into considering because it's something that I think that any person who approaches a mental health service finds immense problems with.

Young people often know very little about the medical system. They are fearful of what they do know. Too often the dynamic is reduced to 'expert' and 'problem' and the person is left outside in the waiting room.

The power dynamic between professional and client is hugely significant and this needs to be addressed. There is no parity of power across that desk. I think in a lot of the DVD's we've been shown today there was that sense of people entering a waiting room or clinic and having no sense of themselves, as being autonomous individuals, of engaging with a service, of having rights and that's something that we're going to keep coming back to over and over.

Young people often have an utter lack of experience in dealing with medical professionals. Many fear they will be forced to take medication which will change their personality. Prescriptions are routinely generated without any discussion – any explanation – essentially without any respect.

The fear of committal is still a huge issue for young people. Even in the most inappropriate circumstances when any doctor would have never considered that this person would need to be immediately institutionalised – a young person can approach a GP with this fear that they'll immediately be taken off in an ambulance. It's almost like a Victorian notion that we've kept but that is informing every young person as they enter the GP's surgery.

Young people have this fear of committal and they're not aware of the rights they do have – those few rights they do have. They need a clear statement of rights. They need a charter. They need a medical system that does not presume. They need doctors who inform, who will explain and who will reassure them through honesty.

It must be frustrating, I'm sure, for doctors or for any kind of medical person to treat a patient who expects a magical cure at their first appointment. But, that patient must still be accorded the value of truth. Information on medication is very rarely made available and without it these prescribed drugs the doctors are so easily prescribing are taking on a very dangerous, mystical aura.

They're something we're afraid to talk about, something we're afraid to ask about, something we're afraid to question. It just seems – we talked about integrity earlier – but it just seems very dangerous to me.

GPs freely offer more information about illegal drugs in their surgeries in their waiting rooms – there are countless brochures detailing the effects of taking illegal drugs or taking MDMA or of taking hallucinogenic drugs – and very, very little about the prescribed drugs. They are the kind of bread and butter of the doctor's clinic.

They'll offer more of this information than about the psychotropic drugs. The effects of which can be equally profound and disorientating for the patient.

Doctors prescribe anti-depressants, anti-psychotics and mood stabilisers to young people every day without affording them security or the dignity or even the basic explanation of how this medication works or what it intends to do.

The scope of common side effects that can be reasonably expected should be outlined with a clear statement that not all side effects should be tolerated. Unrelenting nausea, chronic headaches and extreme somnolence do not aid the achievement of mental well being – not for any person.

There's little space in a doctor's surgery now to explain that the medication which causes the cessation of manic episodes has also left you without the mental acuity you need to understand any of your school classes. That you now dread the lunch time conversation because of the embarrassing five second delay before your dulled brain can grasp the subject. Young people don't talk about these issues to their doctors.

The doctor does not listen when you attempt to explain that that weight gain you're experiencing as a result of the tablets you're taking has made you hate yourself even more. Or, that since your stay in hospital your family regard you suspiciously.

Medics must be enjoined to consider the whole person and to address the public dimensions of a young person's life, if that young person is not to grow to see themselves as nothing more than a troublesome medical problem.

Teenagers are certainly neither trained nor encouraged to question the divine 'doctorly' authority and yet, there are clearly ethical issues involved in the prescription of medication without information.

A mood stabiliser can be prescribed with a casual warning that it will negate the effect of the contraceptive pill, that it will cause birth defects and nothing further. There is no counselling about the prospect of a future tie to such drugs and no attempt to help the patient to deal with what can be very traumatic, physiological and psychological side effects.

Young people have the right to information about their care and about their treatment options. They deserve to be made aware of the different types of supports that might be of use to them. They need their GPs to acquaint themselves with the community supports in their area.

Most importantly, young people need information about their own prognosis. They need to be told that they amount to more than a collection of symptoms. They need to know that they will not always be marked as the possessors of defective brains or minds.

We need to be facilitated to believe in the possibilities of change and growth. We need to believe that things might get better. We need to be supported in finding a way of living inside our own brains. And, when we are afraid and fear that we will never succeed or never survive, we need to be told that change can occur.

The stigma around hospitalisation is still so great that we have stayed silent. We've stayed silent about the experience within institutions and silent about the dearth of support after discharge.

The inherently disorientating, devastating psychological effect of finding oneself at 16, 17 or 18 as a patient captive in a psychiatric hospital is given no consideration.

In addition to the every day challenges with which we must all contend, this young person has been told that their emotions, their cognitive processes, their intuitions, behaviours, their interactions are unreliable. They are treacherous and they are wrong.

In addition to being invalidated by the system, people struggling with mental health are regularly invalidated. There are no magical powers attached to the hospital exit sign and yet, one is expected to immediately acclimatise to an utterly different environment.

After months of physical safety, of surveillance, of routine of monitored meals, freedom is terrifying and this potentially a very, very dangerous time. I think many people would agree with me on this.

There is no preparation for the world outside, for re-entering old patterns, possibly dangerous patterns, for speaking about their experience, for going back to school or going back to college.

If we need psychiatric hospitals, and I believe that we do but in a different form, then they must act as more than holding pens. There's no time or energy given to discussing how an individual might settle back into their job or their studies after six months in an institution – six months out of life. Or, even to how a Leaving Cert student might explain their absence to classmates. Somehow, even very young people are expected to immediately acclimatise to this seismic transformation in circumstances.

Leaving the hospital grounds can mean going from an environment of constant surveillance and routine to total freedom and independence. There's no focus in the hospital. There's no focus in that week before a person leaves hospital on how to learn to be well, how to cope, how to survive, how to explain your absence, how to plan for your life from now on. There's no real planning for the future. No realistic consideration of after care and as we'll go on to talk about, no real follow-up.

In this respect, the system is failing our young people who too easily will fall into believing themselves to be powerless, to be worthless even. Psychiatry must not be allowed to define personality or identity. It is especially a pernicious danger within the context of youth psychiatry.

Many young people leave hospital believing themselves to be in some sense essentially changed beings and they will always be 'ex' psychiatric patients or psychiatric service users. But, they see themselves in a very different way and I think the hospitals needs to work around defining the identity of the young person, allowing them to accept an experience they've had and working on from there towards health.

A young person is very much at risk of attaching themselves to a label that a psychiatrist might throw at them quite casually and writing themselves off as 'crazy'.

'*The Vision for Change*', the document that is kind of the hallowed ground, the thing we might strive for, highlights the particular care which is needed by individuals immediately after discharge. Without adequate preparation and established support structure and an appointment that has already been made, that has been set, that has been written down, that's been inscribed into the future, that we can look forward to, that we plan for, that we can struggle towards, that we can survive until.

Then the sudden liberation from hospital is a terrifying thing and it's extremely dangerous for any individual. It also places enormous stresses on the family and the carers of people who suddenly find this 'ex' psychiatric patient back at home and there's nothing in between and there's nothing to go towards. It's baffling. I can't understand how it works this way…sorry.

Already stifled and stigmatised by an ill informed society, individuals seeking mental health treatment are further denigrated by a mental health system which routinely denies them information and robs them of autonomy.

Most service users in Ireland, I would say, have no awareness that they even have rights – no awareness that they have a right to participate in any decision making processes. Christian was speaking earlier about right holders. But, I think that most young people, in my experience, don't consider themselves as rights holders within the mental health care system at all.

Even when I was sent the brief for today and I read the four topics and I read about participation and complaints and I thought that they are issues that are certainly hugely weighty and important but I'm not sure what to say because I don't think people even know that they have rights upon which to make a complaint.

There was a phrase used earlier of a journey towards rights. I think that's a journey that we're very much just starting out on. I think that in terms of complaints a lot of the problem is that because people don't have a sense of themselves as being even worthy individuals within that system. They're afraid that if they complain they're going to have to use that system again and afraid of what sort of treatment they'll receive at that point. There's no sense of being a clear sort of process to go through. People don't know whom to approach or to whom they should make this kind of complaint.

For any complaints procedure that's sure to be effective it needs to be publicised. It needs to be very easily accessible. A bureaucratic endurance test, such as that described by Gerard so poignantly earlier, will not serve the needs of the vulnerable and it will not serve the needs of the recently bereaved. It needs to be something very simple which we can easily slot ourselves into and fit into a system of making that complaint.

This constructive complaint that you were speaking of earlier, we need to change the way we think about complaints and the way we think about ourselves within the system and mental health altogether.

We have duty break the silence, which has grown out of stigma. We need to make visible and make audible the gross injustices that pervade the mental health system today.

Essentially, we have been talking about basic human rights. We're not asking for anything very exceptional here today. I think that has been underlined over and over by the panel that these kind of hopes that you have for the next 12 months are absolutely achievable and they're quite just and reasonable. But, we just need to set those rights in action.

Thank you.

Inez McCormack: Sarah, at the risk of sounding like a very old person to a very young person, I have many times during my life heard people start in the journey towards rights and the duty starts with that explosion of anger that what you are doing is voicing issues that were absolutely voiceless and a perspective that has not been heard.

But, can I tell you, as you start towards that journey to rights, you have made the most important step forward, in the fact that you are starting to take control of what can happen and how it can happen. And, the important thing that you're doing is making other young people believe that that is possible. That it is not too big to fix – that they can do it. So, thank you very much.

Mental Health Services in Ireland – Comparative Perspectives

Karen Taylor, Regional Coordinator

Irish Advocacy Network

Karen Taylor: Good afternoon everybody. My name is Karen Taylor and I'm a Regional Coordinator for the Irish Advocacy Network and very pleased to be invited here today to speak with everybody.

I hope to provide a comparative perspective from the South. Although the Irish Advocacy Network service is primarily delivered in the acute unit setting to adults, similarities can be drawn with the work of PIPS and RAYS. As we all recognise the importance of empowerment and participation.

In the Irish Advocacy Network our service is client led, providing information and support and promoting choice to users of the mental health services. Indeed, wherever possible our ultimate goal is self-advocacy for each client.

Our aim is to facilitate user empowerment by supporting people to speak up and speak out and take back control of their own life. In order to achieve this aim we're engaged in a variety of activities that include a provision of a range of services, contributing to mental health reviews, North and South.

We provide a range of services that are specifically designed for people who are experiencing mental health difficulties. These services are unique as they are provided by people who previously experienced such difficulties themselves.

Befriending, a listening ear and peer advocacy services are generally provided on the wards, in clinics and in the day care setting, although we do meet clients in the community. By providing information and support and promoting choice for users of the mental health services, people are given the chance to make their own decisions.

If asked, we will speak on behalf of service users when they may temporarily lack the confidence or the capacity to do so. One of our tasks is to build that confidence and give people the capacity to speak for themselves.

So, other sides of our organisation are training and research. The peer advocacy training programme is accredited by the Open College Network and was specifically designed for users of the mental health services.

It aims to enable mental health service users to advocate for themselves and for others. The course consists of ten modules that cover a range of topics pertinent to mental health, including medical and legal aspects, benefits and housing issues and alternative therapies. It also explores key concepts to stigma discrimination and empowerment and seeks to develop listening, communication and negotiation skills.

Other training we provide includes volunteer training, which attempts to match the talents of the individual to a setting where those talents would most appropriately be used. Staff awareness training is delivered regularly to nursing staff within the HSC and to training nurses.

A general principles of advocacy education module is in the process of development and accreditation by Fetac. We also presented a training module in mental health awareness to solicitors, lay-people, Grade 5 and mental health commission staff from the service user perspective at the request of the mental health commission in preparation for the Tribunals.

Research is an expanding side of our organisation. The Irish Advocacy Network has carried out a variety of audits, needs assessments, surveys and satisfaction reports.

I would like to take this opportunity to briefly outline the main role of an Irish Advocacy Network Advocate. Their role is to provide a peer advocacy service in all acute units or approved centres and their HSD region on a weekly basis.

This service entails provision of information and support and the promotion of choice. In addition, as an organisation we have a nation-wide remit to provide information and support to people detained under the 2001 Act.

Peer Advocates provide an ad-hoc service to day care facilities and some training centres. The service is client led as it matches the needs of the client at that time. And through active listening we can help clarify and help prioritise the issues with the clients.

So, I'm now going to move on to the legislation and policies introduced by the Irish Government, which affect mental health service users and providers.

The most significant development in mental health in the Republic of Ireland for quite some time is the implementation of the Mental Health Act, 2001, on the 1st of November 2006. There was a bit of a gap there.

This Act replaces the 1945 Mental Treatment Act and brings Ireland into line with the European Convention in Human Rights. I might add that it just about brings them into line and no more.

The 2001 Act establishes the Mental Health Commission and the Mental Health Inspectorate and legally defines their roles. *A Vision for Change* is the report of the expert group on mental health policy and sets out a comprehensive policy framework for mental health services in Ireland for the next ten years and it's in the process of being implemented.

So how do these government initiatives affect people using the mental health services? What impact do they have at grass roots level? The 2001 Act has now been fully implemented for over a year and although significant in itself it should be viewed as one part of ongoing reform. It enshrines and protects the rights of mental health users for the first time in Irish law. Under this legislation, anybody who is involuntarily detained has an automatic legal right to an independent review in the form of a mental health tribunal and must be informed at every stage of the process.

Although there may be teething problems, such as logistical considerations, bringing some consultant psychiatrists on board and some clients not receiving the necessary information, this legislation has brought Irish law into line with European Human Rights Conventions.

The four key principles of the Act are: the right to review, the right to information, the right to have standard of care and the best interest of the person.

The 2001 Act establishes the Mental Health Commission. The main thrust of the commissions work is ensuring the rights of service are upheld. This sets the minimum standards which inpatient facilities providing mental health care and treatment must meet in order to be able continue operating.

They also issue legally enforceable rules and regulations proscribing how various procedures and practices such as ECT, seclusion and restraint must be carried out. It is a criminal offence not to adhere to these rules and regulations and failure to comply could mean that a facility loses its approved status.

The Commission also oversees the tribunal process. They must be informed of every detention, the outcome of every tribunal and they appoint the tribunal members. This means that an independent body with very extensive powers is at all times overseeing and enforcing the rights of the service users. And, I might add too that the Mental Health Commission in the Republic take their duties very, very seriously.

The Mental Health Inspectorate is also appointed by the Commission. They inspect all mental health inpatient facilities where treatment is provided and have a legal duty the rules and regulations produced by the Commission are complied with.

The Inspectorate has all powers at their disposal and failure to cooperate is a criminal offence. The Inspectorate have the power to remove a facilities' approved status if it does not meet the required standards established by the Commission. Again, the Mental Health Inspectorate also take their duties very, very seriously.

The Vision for Change, although only in the process of implementation, espouses partnership working, community-based services, the use of Recovery Model rather than Medical Model, and service user involvement at all levels. With this policy framework document the language is right but it's just the tip of the iceberg. It needs to be fully implemented for meaningful and lasting improvements to be felt at grassroots level.

To demonstrate how these legislative and policy initiatives are working on the ground I'm going to provide a brief outline of how our advocates operate under these developments. Our role has changed under the 2001 Act as providers of information and support as our advocates have a specific role to play in relation to people who are involuntarily detained.

The advocate, in partnership with staff on the ward, access clients who wish to see us under the Mental Health Act, 2001. Very often the service user is angry, confused and fearful. Through actively listening to the person's story in a non-judgemental way in an independent capacity we can place value in that service users experience and help alleviate some of their concerns.

It is the advocate's remit to ensure that all people detained under the 2001 Act have accessible information on legislation. This is contained in this book here, '*Your Guide to the Mental Health Act, 2001*', which is very, very user friendly and each patient should be given one of these on their admission to hospital.

It is the advocate's job to go through this book and explain it to the client, if that is what the client wants, or answer any questions the client might have. If requested by the service user, the advocate will provide support throughout the tribunal process.

This may include some of the following: explaining or reassuring the service user that the tribunal process is in the person's best interest in accordance with the European Convention on Human Rights and that the tribunal process should be non-adversarial. Checking, facilitating, administrating, if necessary, for example the dates and times for the tribunal and ensuring that information, if necessary, is disseminated to relevant people, for example, the solicitor or the second opinion psychiatrist.

Again, if requested by the service user the advocate will accompany them to the tribunal and if agreed with and deemed necessary by the service user, speak on their behalf. The advocate will offer and provide debriefing and ongoing support to the service user if this is what they want.

This is a good example of how government policies and programmes have been implemented in a way that serve to ensure the rights of a very vulnerable group of people are protected and provided with the information and support they need.

So, this final slide is a brief overview of the main issues arising for service users of inpatient facilities in North Dublin. As our service is provided at the coalface we are very well placed to listen to the issues arising from a service user's perspective and feed them back to the service providers. Indeed, we have developed formal reporting mechanisms with the Mental Health Commission and Inspectorate to ensure these issues are addressed.

Due to the focus of partnership working we also have reporting structures within the acute units so issues can be dealt with promptly. These measures, together with the introduction of consumer panels in the hospital setting and service user involvement in designing service delivery, have gone a long way to ensuring less and less issues arise and that all issues are addressed.

A main concern for service users is medication and information around medication and diagnosis. Many clients feel there is an over reliance on medication and we have discovered that although service users should be provided with information on medication and diagnosis from their doctor this does not always happen. We've found that some clients have received no information or information that is neither balanced nor comprehensive. Of course, we will try to provide this type of information to clients if they ask us – and they regularly do. And this is an issue we've brought to the attention of the Mental Health Inspectorate as well.

The need for discharge planning has been highlighted to us and we've reported this to the service providers and it is now an area in which they're seeking to approve. So, hopefully, this will have a huge beneficial effect at grass roots level in the near future.

Access to services is another common issue for service users. By this I mean access to social workers, psychologists, occupational therapy or talking therapies. However, this problem is down to lack of resources, both financial and human, rather than a lack of will on the part of the service providers. However, *A Vision for Change* states that a multidisciplinary team approach is essential in mental health care and treatment.

We are hopeful that the full implementation of this policy will address the needs of our clients. We will continue to contribute to the implementation of this policy at the highest level.

Finally, I've listed complaints under other issues. I gather it's an area of concern for service users in Northern Ireland but is not an issue that crops up so much for us in the inpatient setting across the border.

In the Republic there is a clear complaints policy and procedure in place by law for the HSC and voluntary organisations and that is something that legally has to be done. In fact, service users are encouraged to complain and the HSC, *Your Service Your Say* leaflet and guidelines are available on each acute unit and are visibly displayed. And, of course, or advocates are always available to facilitate clients in accessing these complaints structures and support them through the entire process.

So, to round off, I hope this give you an insight into the work that our organisation does and a useful comparative perspective from the South or, in short, let you know how things are progressing across the border in the acute units setting.

New policies and initiatives by the Irish Government have greatly helped us in our jobs providing information, support and choice for people who use the mental health services. However, the task is by no means complete and there is still much work to be done in ensuring and protecting the rights of our most vulnerable people.

Thank you.

Written Questions from the Floor

Inez McCormack: Okay, thank you Karen. We made connections with Karen and with Headstrong with both the help of our local staff in Dublin and also with Combat Poverty in terms of Louise. We hope the connections will thrive because I think we can learn a lot from each other and perhaps we can develop some of this work together because if what you've got is working we'll use it and if what we've got is working you'll use it, okay?

I think we should give time to the panel now. But, may I just deal with some of the questions and queries that came in. The panel may deal with some of the general issues but not so much the specific. There's a question on suggesting ways to change attitudes to lesbian, gay and bisexual young people in this society. I think one of the panel is going to deal with that under the issue of disaggregation.

There is a question on political accountability – how do we make political representatives and people in power make changes and put benchmarks in place? I think this is part of our work here in terms of trying to ensure that the Minister becomes the duty bearer and that we use the new devolution to try and get these issues to the scrutiny committees and get a cross party response. I mean that has got to be a lesson – things we've got to learn how to do and they've got to learn how to do.

There are a number of issues and I think Gerard's dealt with it – there's a question on how do we treat youngsters who are not regarded as mentally ill but, in fact, are clearly distressed and confused and are possibly suicidal. I think, no answers, but some of the strategies are beginning to come out in terms of the preventative community response. Again, I think the panel will be dealing with that in their broader reflections.

Also, I think somebody put in this question from Acorn about the mental health services being so 'un-understandable' if there is such a word to people actually experiencing the problems. Again, how do you get a flexible community response?

I think there have also been a number of questions around the notion of the Psychiatric Model and the Medical Model which are very much unaccountable models. The question is how that level of accountability can be altered in terms of political accountability. Secondly, another way that we can intervene is in the training mechanisms of psychiatrists. So, instead of talking about the individuals it's trying to change the system. I think the panel will deal with that in their broad reflections.

Then Olga's question about borderline personality disorder. I think the problem is when you don't fit the system; the system tells you to go. I think that's the answer Olga. I think there are no easy answers. I think the panel will have general reflections in terms of someone who doesn't fit the system. How, in fact, you can get response but in terms of the more specific issue the question is how can we assist you to get some response when doctors go and they're not replaced and when frankly, you're a troublesome patient that people don't want to listen to. There are no easy answers to that but I think we'll try to do some follow up.

Is that okay? Thank you very much. Okay, over to the panel.

Final Reflections and Panel Feedback

Christian Courtis: We'll just start wrapping up a number of points on what we've heard and what we can offer. The first has to do with what is the rationale of bringing someone from Geneva or Washington, D.C. to something that looks very local. Is there any connection with services in North Belfast or is this just putting people together trying to speak about the same topic with no connection? And I would say, this is a dialogue that is a two way process. From our viewpoint some international input could be useful as a resource for you.

The way in which you have used some of them is very creative. The fact that some international obligations by the UK are taken seriously means you can use some of those tools, such as the notion of progressive realisation or the idea of identifying duty bearers, etc. as one of the ways in which you devise your strategy towards action, towards claiming rights.

I think that we may have at least illustrated a little bit about other possible resources and using this international jargon that seems to be far away from local experiences.

On the other hand we have received input about how to do some of these things in real settings in real communities with real problems. So, we will take this as a good example. It could be replicated elsewhere. It's very creative. Notions of indicators and benchmarks have been debated in the academic field but using them as a monitoring tool well, there's not much experience in this perspective through civil society groups.

So, this is a great example that can be replicated and I would be happy to spread the word in other groups that are doing the same in the mental health field and in other fields regarding health services that are accountable for people.

A second line is connected to this. It has to do with an area we are speaking on – Human Rights. Rights mean something more than white paper. When you speak about rights, you speak about a number of elements that should be fitted in, in order to consider them seriously. So, if we speak about rights we speak about a rights-holder, we speak about someone who is accountable, a duty bearer. We should speak about what is the content of the right, what we are entitled to and what are the limits of the right. And, what are the mechanisms to overview and supervise, the compliance with that right.

So, the exercise you did today offers us a number of inputs that touch some of those elements – trying to spot the notion of rights through the perspective of the right holders – positioning yourself as right holders means a big change, it's not only a passive user of a service but someone who has rights and who can claim rights.

Then trying to identify who is the duty bearer. It's not just a community in general, it's not just a state in general, it's not just mankind in general but there are some government officers that should be held responsible for a number of things and pinpointing these duty bearers is important in order to make accountability happen.

The exercise of using specific indicators also touches on some of the elements I've mentioned. So the follow-up and the information from GPs touches on how to define the content of the right and how can you grapple on what the right means. And the other two issues on participation and complaints also touch on what the other procedural mechanisms are in order to make the rights not only be a promise or an aspiration but something that can be accountable.

Just the last thing regarding one of the questions. There may be some other steps forward and one has to do with the fact that as an initial step only having the crude or general information is not enough because the state has a special duty to take into consideration groups that are vulnerable or marginalised and take positive action to those groups.

Within each community a number of factors will mean different members have different levels of access to services. So, before taking action and before pointing to the need to take action data on who are these groups that need special consideration should be collected in order to claim the special action. So maybe a further step here is breaking down the data you have to try to spot if there are special groups that would especially need some attention.

Thank you.

Inez McCormack: Thank you Christian. May we move on to Tara.

Tara Melish: Great. I really want to thank all of you for having us here. It has been so enriching for us and I feel that we weren't able to provide very much but we got so much from you that we are going to bring back to our own communities. As we mentioned, this model of holding government accountable to human rights mechanisms hasn't been used in other parts of the world. That is, in most places we talk about governments identifying their own indicators or international bodies identifying indicators and then having government respond to those indicators that are defined by other people.

In the US we have a government who define indicators. With respect to poverty, for example, we have indicators that are showing wonderful progress while poverty is increasing because they are not measuring the right things. That's why it is so important that communities are the ones who themselves define what the indicators are to make sure that the indicators truly serve as a metric for human well being.

So, that is what is so exciting about this project and what we plan to take away. And, I hope that you and your own organising can use that – can use our presence here and our enthusiasm for this project and our capability and our intent to bring this model back to our own communities. So that this will really be seen as a best practice.

When you're talking with your national health authorities and with the Human Rights Commission that you say, that this is seen as a best practice or this has the potential of being a best practice, so let's make it really work because there is going to be international attention to what is happening in North Ireland. People are going to be talking about it, people are going to be writing about it, and people are going to be going to international conferences and talking about this model.

So, I hope that that can be used here and that there is a firm understanding of really the innovativeness of this project and how important it is for communities around the world who will begin to be adopting this model.

I want to say a couple of things. One of them is that this particular model focuses very much on progressive realisation. Sometimes there's too much, in my opinion, emphasis on progressive realisation and an understanding that the right to health as an economic and social right only has obligations attached to it that are of progressive realisation and not obligations that are immediate. The civil and political rights have immediate obligations and economic and social rights have progressive realisation.

It's important to always keep mind that that's not true. There are immediate obligations and there are progressive obligations that apply to all human rights. When we are talking about progressive realisation with respect to the right to health we want to monitor that through obligations of result or these outcome indicators that we've been talking about here and as part of this project.

There are also conduct-based obligations which specifically using the language of human rights treaties is the duty to take all appropriate measures to realise rights. So, there if we're identifying those conduct-based obligations we're going to identify the appropriate measures that states should take to realise rights.

So, there are two different models here. One, the model of this project, which is focusing on outcome or result indicators and putting benchmarks to them which can lead to some very, very important results and processes. The other is focusing on identifying appropriate conduct for the state to undertake. In some of the suggestions we've been mentioning some of those. For example, suggesting a particular course of action as an appropriate strategy. We can suggest those to government and those are obligations of immediate affect. The obligation of progressivity and the availability of resources come into account in terms of whether it's an appropriate measure because states can only use the resources that are available with respect to whatever right we're using.

So, that's another way to think about it and when we're engaging in these strategies to always keep in mind that we can be creating indicators in both realms – outcome-based indicators and process-based indicators.

In other parts of the world where we are seeing a real focus on trying to think creatively about how we can create new institutions or new mechanisms for participation so that people's voices can really be taken into account.

We've been seeing this other model being used of focusing on the process-based indicators. I'll give you just two examples. One in South Africa that took place in 1998 and one in the US that took place last year. Both involved what were called national poverty hearings. They were national level hearings. In South Africa there were ten hearings that took place in each of South Africa's nine provinces in which people came together around thematically organised hearings. One of those thematically organised hearings was on the right to health.

So, people came together. In South Africa 10,000 people participated in this process in order to provide on an official record their own personal experiences. Their own personal testimonies about their experiences with the right to health and what they identified as obstacles to their achievement of the right to health and their own solutions. How do we overcome those obstacles?

So, it was a process of one, a public record, two, personal testimony, three, proposed solutions and then they put together, fourth, an accountability plan. That is they wanted to make sure that identifying these solutions was going to go somewhere. That they weren't just going to remain in that particular forum.

They put together a national poverty commitment in which they had individuals sign on individually that they were going to take specific measures that were related to the obstacles and solutions that were identified in the hearings. They had different sets of commitments that were made by individuals in civil society, by the media, by government, people in public/statutory agencies, for example. Then they could move on from that direction.

That model was very much focused on what are the measures that we want the government to take and how are we going to get them to do it. Which again, is a different model but something that we're seeing more frequently in other parts of the world but has very recognisable drawbacks in the inability to monitor consistently as this project is doing.

We've seen the same national poverty hearings take place, or something very similar, in the US last year. Also including hearings on their right to health as well as the right to education, etc. I just wanted to raise that as another possibility but also to underscore that nowhere else in the world right now that I think any of us know of are people doing what is being done here.

Finally, I want to emphasise is that none of this work happens without institutional connections, institutional mechanisms between what is happening at the community level and government. There needs to be those institutional mechanisms set up so that there is a constant communication back and forth on how well we're doing. And, if there are changes that need to be made or new proposals that should be made those inputs need to brought into the process.

So, one of the most important things starting out is to make sure that those channels of communication between this group and the human rights commission – this group and the health ministry – this group and the trust is established right from the beginning so that this process can really go forward and be effective and be that best practice that we're going to see emulated around the world.

Thank you.

Inez McCormack: Thanks very much Tara. I mean I have to say there was this plot going on in my head as I was listening to her about holding a hearing in North Belfast and bringing these processes together and needing 10,000 voices to be heard. However, perhaps that's next week, Nicola, Stephanie? (*laughter*)

Camilla?

Camilla Parker: I think that anybody who had any doubts this morning will have no doubts now that what we're talking about is an incredibly challenging area. The issues in relation to mental health and the way that we support or rather so often don't support people who experience mental health problems. You could almost become overwhelmed with the problems to be addressed.

I would first of all like to start off by congratulating all of the people involved in the project and I suspect spending a huge amount of time talking through the issues and really working out what the key issues of concern are – having heard a very long list then trying to pare that down. I think it's really important that what has been done is to look at some areas which I think are of key importance but then to look at how you can address that in a manageable way.

I echo my fellow panellist's comments about how exciting a project this is. I think all of us agree that the way you've presented this is something that is manageable and you will be able to see the difference that you're making. I think this is incredibly important because the problems are so enormous I think it's important to think, 'well, how are we going to start this process?'

Reflecting on Sarah's presentation I think it is really important to think of this as a journey. I think that term has been used a number of times. Sarah's presentation really shows that for many talking about human rights is in a different universe when you're in a psychiatric hospital. You're going through incredible mental distress and you're surrounded by other people who are suffering similar but different experiences. It can be a very scary time and thinking about what your rights are when you're being told, 'well, take this medication and go away' - it becomes something that is very difficult to grasp hold of.

I think in this kind of project we need to remember that – we need to remember that what we're talking about is working with people who have for so long been considered not to have rights. From the tradition, I think Northern Ireland and Ireland are similar to the UK where we put people in institutions and chose to forget about them. To some extent while we have moved on in many ways there still is this concept of questioning people with mental health problems as whether they have rights at all. I think it is really important for us to hold on to that when thinking about these issues.

That's why this project is so important because it is making human rights come alive. It is taking steps to make a real difference to people and to all of us because as a society we need to look at the issues around mental health. We need to think about them in the same way as – there's lots of concern around obesity, for example. These are issues as a society we have to work together at to try and resolve and respect each individual and listen to each individual and value people's contributions to engaging in dialogue for how we are going to change things.

So, I think the indicators are incredibly important because they set it out in black and white – this is what we are trying to achieve. I think it provides an opportunity for that dialogue between people who use mental health services; people who are in the job of delivering service and for people who are commissioning them. There are many people might be in at least two of those categories.

It's about working together because I think it is really important that we do. I think it's important to engage with human rights activists who might not necessarily think about mental health as a human rights issue, which again, is why I'm so excited about this project because it is really making human rights real and looking at how we can address issues relating to mental health.

So, I think probably I've said enough. Thank you very much, everyone who's here, like Tara, I've just learned so much. I'll go back home and feel really inspired by what is happening here. Hopefully, we can exchange ideas and learn from each other because going back to that journey where we started the journey but there is a long way to go and we'll need to help each other along the way.

Thank you.

Chair Closes

Inez McCormack: Okay, I think in terms of the panel, god help them, they got phone calls or emails out of the blue. They didn't know anything about us but I think Camilla summed it up. I think they recognised we're actually trying to be on a journey – all three of you are on that journey as well, in terms of the journey toward making rights real for those who need them and enable them to use them. So, I think, in fact, that's why you came.

I said to you a bunch of times but I think Oonagh said it better than I did that not only in terms of listening to us and validating the work of the groups and the work that we're trying to do is that you've helped us take a step forward. And Oonagh said, 'no, you didn't help us take a step forward, you helped us take a HUGE step forward!' So, on behalf of all of us, thank you for coming and thank you for helping us to take the next step.

I also had dinner with the panel last night and made them aware of something. Anybody who knows me here knows it's very, very true that once you get to know us we never let you go. So, the panel will be meeting afterwards. They've given you immediate reflections. We are going to prepare findings, which we will publish and launch. This will be the basis of our meeting with the Minister, with PIPS and RAYS, setting the agenda as they have, and the panel supporting them and the Rights Project supporting them and ensuring that those targets and timetables and further developments of how we do our work are actually turned into tangible change. That's our next step. The panel will be staying with us on that journey in one way or another, god help them, for however long it takes.

The second thing and I think I can say this on behalf of the panel and on behalf of the people here as well, is this is not possible without people who are the true human rights activists in the worlds. When you're in a corner and something appalling has happened to you or somebody belonging to you, there are different ways of handling it. By getting out of that corner, by asserting the right of yourself or the person to whom this happened in a way that asserts their dignity but also thinks I'm going to assert it in terms of the dignity of others – that is a true definition of human rights activist. And, on behalf of all of us, I would thank the human rights activists in PIPS and RAYS for what they're doing to set standards for that.

Can I just read you out my note to speaker here? As we get to the end it says, 'no big thank you to staff we all get embarrassed!' Could we thank the staff and embarrass them?

Nicola and Stephanie have been the most visible. They have led this work, both in terms of the development with the groups and in doing this extraordinary difficult work of turning the abstract into practical concrete outcomes. But, I think they both would say this couldn't have happened if the staff hadn't worked as a team.

There's Avril here who's done the hard grunge work of making this happen and stood and watched me with a glint in her eye as the hot food went cold. That was her benchmark.

But also, in terms of Oonagh and all the staff and Maeve who is up here from Dublin, who helped to make it happen and Dessie who is on holiday. Can you thank them again? They get really embarrassed.

Thank you all for coming and thank you mostly this afternoon for all of you who stayed. I know that many people did have other commitments. This is the beginnings of a difficult journey and this is no secret any work that we do, any work that we try to do, none of it will be perfect. It will be clues in a long, long struggle. It is welcome to all of you to take it and use it in whatever way that is useful and helpful to you. We're not publishing some expert result in a few years time. As we go along, as we do this work, we share everything we do because there will be somebody else who will think of something else and they'll think of something smart and they'll do it and then we'll steal it back again! And that's the way we learn.

Thank you all very much indeed.

Appendix 1

Biographies of Panelists and Speakers

Professor Tara Melish, University of Georgia, USA

Professor Melish specializes in the legal protection of economic, social and cultural rights in a variety of institutional settings. She has served as Staff Attorney and Legal Advisor to the Center for Justice and International Law, a law firm specializing in litigation before the inter-American human rights system; as Associate Social Affairs Officer in the Disability Unit of the United Nations Department of Economic and Social Affairs; and as Mental Disability Rights International's United Nations representative in the drafting negotiations of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol. Active in reporting procedures and litigation initiatives before UN and OAS bodies, Professor Melish serves as consultant or adviser to a range of domestic and international organizations, publishes and lectures widely on human rights issues, and has taught on human rights law, international litigation, constitutional law, criminal law, and torts at a variety of law schools, most recently at the University of Georgia and University of Virginia Schools of Law and Oxford. She has clerked on the U.S. Court of Appeals for the Ninth Circuit and the South African Land Claims Court, received professional fellowships from the MacArthur Foundation, Fulbright Foundation, and Yale Law School, and has degrees from Brown University and the Yale Law School.

Christian Courtis, International Commission of Jurists, Geneva

Christian Courtis is the Legal Officer for Economic, Social and Cultural Right for the International Commission of Jurists, Geneva. He holds a Bachelor in Law and a Law degree from the University of Buenos Aires, Argentina, and a LL.M. degree from the University of Virginia, U.S.A. He is a law professor at the University of Buenos Aires Law School, and invited professor at ITAM Law School, Mexico City. He has acted as consultant for the World/Pan-American Health Organisation, UNESCO and the UN Division for Social Development. He was a lawyer for a human rights NGO in Argentina, Centro de Estudios Legales y Sociales (CELS), legal counsel for the Argentine Senate, and legal clerk for the Buenos Aires Suprema Court. He has worked in legal reform issues in Latin American, Caribbean and African countries. He was a legal adviser at the Argentine senate and a law clerk for the Buenos Aires Supreme Court. He has published books and articles on human rights, constitutional law, legal theory and sociology of law.

Camilla Parker, Mental Health and Human Rights Specialist, UK

Camilla Parker is a legal and policy specialist in mental health, disability and human rights. She is a consultant to the Open Society Mental Health Initiative (MHI). MHI seeks to promote the human rights and social inclusion of people with mental health problems and/or learning disabilities in Central and Eastern Europe and the former Soviet Union. Her publications include: *Developing mental health policy: a human rights perspective in Mental Health Policy and Practice Across Europe*, editors Martin Knapp et al, McGraw Hill, Open University Press (2007) and *Independent Living and the Commission for Equality and Human Rights*, Disability Rights Commission, http://www.drc-gb.org/PDF/CEHRJan1full%20report.pdf January 2007

Inez McCormack, Chair, Participation and the Practice of Rights project

Inez McCormack is chair of the North/South Participation and 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 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 a 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". These include the Eleanor Roosevelt Award from New York City. She was awarded an honorary doctorate from Queen's University Belfast in 2000 for her services to human rights and the community. 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.

Laura Niwa, Policy Officer, Law Centre (NI)

Laura Niwa is a Policy Officer at Law Centre (NI) specialising in mental health, community care and social security policy work. A previous analyst for the New Zealand Ministry of Health on mental health and disability issues she gained further experience in mental health and incapacity issues as a caseworker for people diagnosed with a mental injury as a result of sexual abuse or sexual assault. While completing her LLM (Hons) at Auckland University, specialising in social, economic and cultural rights and indigenous peoples rights, she was a legal researcher for the New Zealand Human Rights Commission.

Jo Murphy, Co-ordinator, PIPS (Public Initiative for the Prevention of Suicide)

Jo Murphy worked as a health and social wellbeing development officer in North Belfast before establishing PIPS (Public Initiative for the Prevention of Suicide) with Philip McTaggart, who lost his own son through suicide. PIPS was established in 2003 following a cluster of suicides in the North Belfast area. Jo and Philip worked to establish an organisation that would go some way to try and fill the gap in services for both those in crisis and bereaved families. The organisation is named after Philip's son, whose nickname had been Pip.

Nuala Smith, Headstrong

Nuala Smith is a youth participation officer with Headstrong, which works to empower communities to support young people in Ireland aged 12-25 to achieve better mental health and wellbeing.

Sarah Hayden, Headstrong

Sarah is a member of the Youth Advisory Panel with Headstrong.

Karen Taylor, Irish Advocacy Network

Karen Taylor has worked for the Irish Advocacy Network for 4½ years and is currently their Regional Coordinator for the Dublin North East HSE region (Cavan/Monaghan, Louth/Meath, North Dublin county and city).

Roberta Coates is Co-ordinator of RAYS Crisis Centre and works with people in mental health crisis and their families. She is also a member of the PIPS/RAYS rights group.

Gerard McCartan is a member of the PIPS/RAYS rights group.

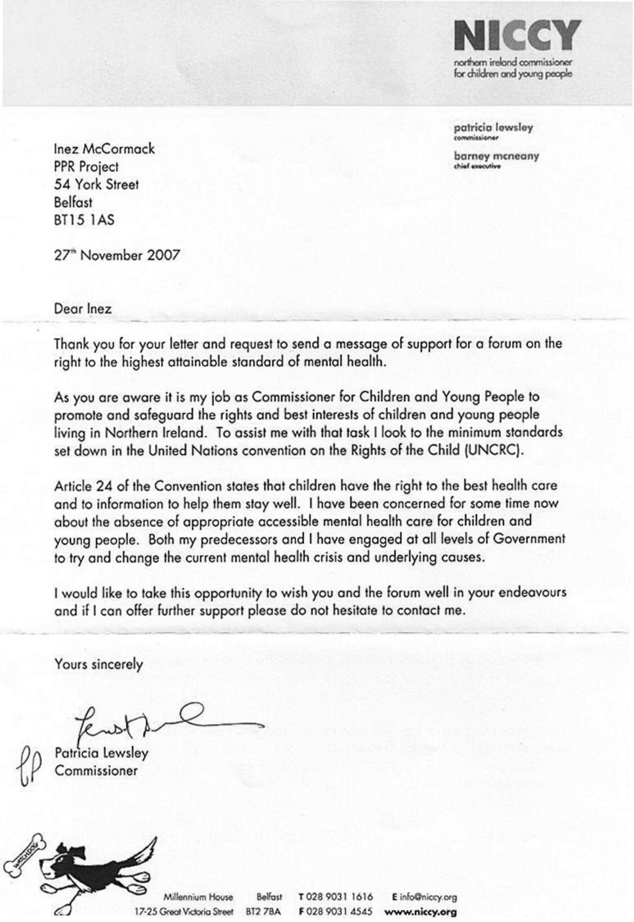
Jean Hand is a member of the PIPS/RAYS rights group

Nicola Browne is a Policy and Research Officer with the Participation and Practice of Rights Project in North Belfast

Stephanie Green is a Local Development Worker with the Participation and Practice of Rights Project in North Belfast

Appendix 2

Messages of support



NICCY
northern ireland commissioner
for children and young people

patricia lewsley
commissioner

barney mcneany
chief executive

Inez McCormack
PPR Project
54 York Street
Belfast
BT15 1AS

27th November 2007

Dear Inez

Thank you for your letter and request to send a message of support for a forum on the right to the highest attainable standard of mental health.

As you are aware it is my job as Commissioner for Children and Young People to promote and safeguard the rights and best interests of children and young people living in Northern Ireland. To assist me with that task I look to the minimum standards set down in the United Nations convention on the Rights of the Child (UNCRC).

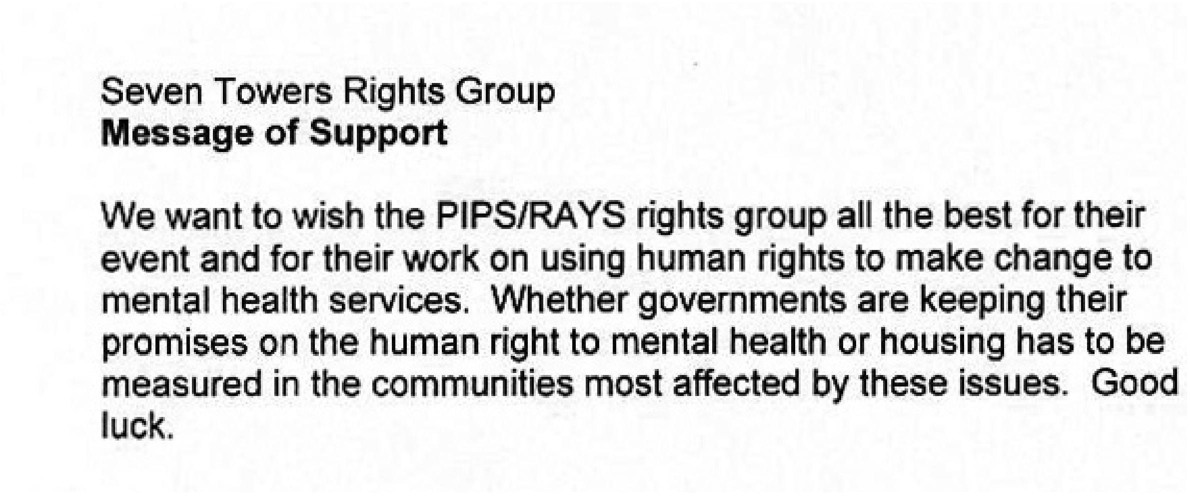
Article 24 of the Convention states that children have the right to the best health care and to information to help them stay well. I have been concerned for some time now about the absence of appropriate accessible mental health care for children and young people. Both my predecessors and I have engaged at all levels of Government to try and change the current mental health crisis and underlying causes.

I would like to take this opportunity to wish you and the forum well in your endeavours and if I can offer further support please do not hesitate to contact me.

Yours sincerely

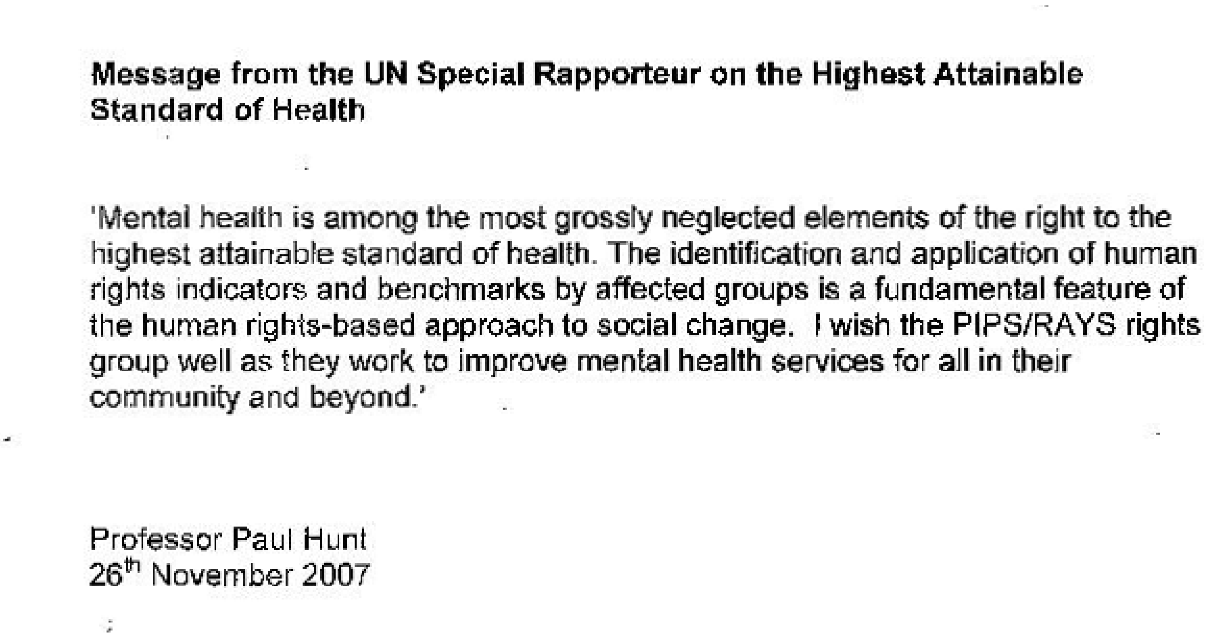
pp Patricia Lewsley
Commissioner

Millennium House Belfast **T** 028 9031 1616 **E** info@niccy.org
17-25 Great Victoria Street BT2 7BA **F** 028 9031 4545 **www.niccy.org**



Seven Towers Rights Group
Message of Support

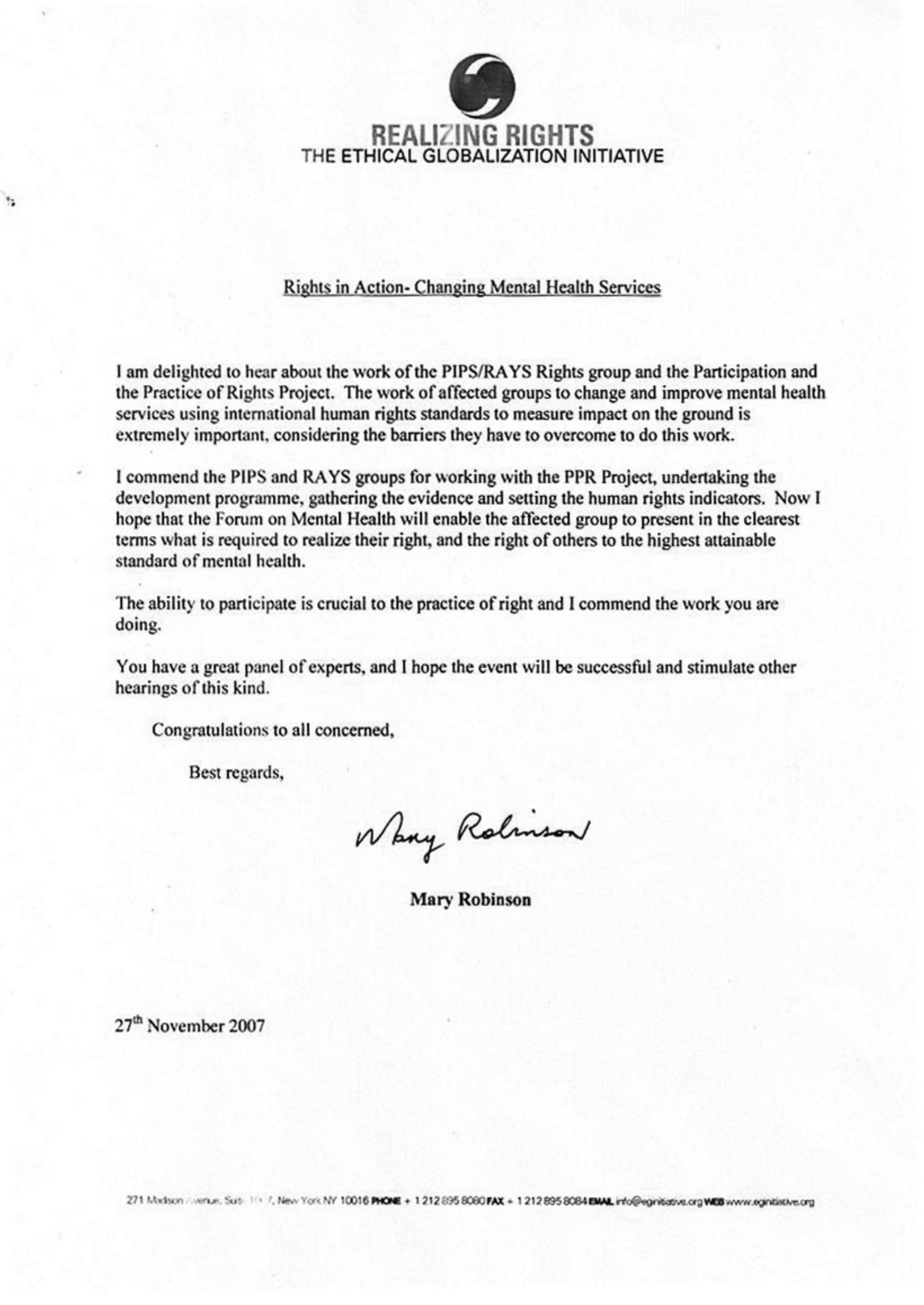
We want to wish the PIPS/RAYS rights group all the best for their event and for their work on using human rights to make change to mental health services. Whether governments are keeping their promises on the human right to mental health or housing has to be measured in the communities most affected by these issues. Good luck.



Message from the UN Special Rapporteur on the Highest Attainable Standard of Health

'Mental health is among the most grossly neglected elements of the right to the highest attainable standard of health. The identification and application of human rights indicators and benchmarks by affected groups is a fundamental feature of the human rights-based approach to social change. I wish the PIPS/RAYS rights group well as they work to improve mental health services for all in their community and beyond.'

Professor Paul Hunt
26th November 2007



REALIZING RIGHTS
THE ETHICAL GLOBALIZATION INITIATIVE

Rights in Action- Changing Mental Health Services

I am delighted to hear about the work of the PIPS/RAYS Rights group and the Participation and the Practice of Rights Project. The work of affected groups to change and improve mental health services using international human rights standards to measure impact on the ground is extremely important, considering the barriers they have to overcome to do this work.

I commend the PIPS and RAYS groups for working with the PPR Project, undertaking the development programme, gathering the evidence and setting the human rights indicators. Now I hope that the Forum on Mental Health will enable the affected group to present in the clearest terms what is required to realize their right, and the right of others to the highest attainable standard of mental health.

The ability to participate is crucial to the practice of right and I commend the work you are doing.

You have a great panel of experts, and I hope the event will be successful and stimulate other hearings of this kind.

Congratulations to all concerned,

Best regards,

Mary Robinson

Mary Robinson

27th November 2007

271 Madison Avenue, Suite [illegible], New York NY 10016 **PHONE** + 1 212 895 8080 **FAX** + 1 212 895 8084 **EMAIL** info@eginitiative.org **WEB** www.eginitiative.org

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23rd November, 2007

Participation and the Practice of Rights Project
Rights in Action: Changing Mental Health Services
54 York Street
Belfast

Dear participants in 'Rights in Action: Changing Mental Health Services,'

I am very sorry I can't be with you today, however, it's a great honour for me to be able to support, even if just symbolically, the beginning of your journey in shaping the future of mental health services in your communities.

I have been very excited to learn about Participation and the Practice of Rights Project, which tackles the core of human rights - the right to participation – and provides the communities the opportunity to actively engage and advocate for their rights.

During my short experience in the field of human rights for people with mental disabilities, I have learned that most successful mental health services and community supports are those that are planned and provided in equal partnership between service providers and service users, for one reason that they have been tailored to best meet the users' needs. I believe you have a good chance to make your mental health services one of them.

Finally, I want to applaud the PPR Project for bringing you together today and I wish you a very productive day. I am looking forward to learning about the results and to our cooperation in the future.

Warm regards,

Dea Pall

Dea Pallaska O'Shaughnessy

mdri

1156 15th St NW, Suite 1001, Washington, DC 20005
Phone: (202) 296-0800, Fax: (202) 728-3053
E-mail: mdri@mdri.org
http://www.mdri.org

Appendix 3

Experiences paper

Experiences of Mental Health Service Users in North Belfast:

A Baseline Survey

Prescriptions

“I’ve been on these tablets for years and years, I’m addicted to them.”

“I never see a doctor, I just get a repeat prescription.”

“Now, I’m addicted to them because I’ve been on them that long. It doesn’t make any difference what information…I can’t remember what they told me before they gave them to me. They just gave me them.”

“Most people you would actually speak to would agree, GPs just write you scripts for anything, antidepressants and all the rest of it, we were talking about it a minute ago, it’s that simple. I ring up for a repeat prescription and as long as, I personally feel, as long as you are not taking up their surgery time they are happy enough to write you another prescription.”

“He gives him medication he has had before that he won’t take and he won’t say he has a drink problem because nobody will sit and give him the time to work it out….He doesn’t want to lose what he has but at the same time he doesn’t want to keep it, life’s not worth living…”

“Oh yes, that’s the way I am, I’ve been on those tablets for years, I’ve been on them that long I cant remember. I went home and ordered a prescription one time about 2 years ago and one of the other doctors told me I would have to wean myself off them, it’s easier said than done, when you have got so used to taking these.”

“I would be on lithium and you have to get your blood taken, and you have to have your kidney and different tests each year, you know, it’s very important that you get them done, but I know quite a lot of people on this and they don’t know anything about that. They don’t know about the blood tests, how often they should be getting them, what they should be doing. I would be totally horrified, because if you take an overdose of lithium, even accidentally, it can be very, it can be fatal…But I think it’s difficult. Some people may not be able to manage or understand all that. Do you know?”

“I’m not saying all doctors are the same, I’m not here to slate them all, but, the doctor I’m with at the minute…He’s a toughie, like, you’ll get nothing with him! And that’s not a bad thing, you know, really, I honestly believe that’s not a bad thing, you know? Because there are some doctors, as you say, with pills, oh, that’s not working, well, try this. And he will not give me anything. He’s on that computer looking it up and telling you every- he tells me every side effect that’s on that tablet…and I thought how many doctors take the time to do that?”

“Then I wonder, is it a mix of time, and ignorance, and pressure, and money, of course, at the end of the day, and I mean, realistically, I think the turnaround for a patient is seven minutes. Now, in seven minutes, you barely get your name and address out really, let alone what’s wrong with you, like, kind of a history of how you’re feeling.”

Experiences with Doctors

“We were with one doctor about my mental health, I went to my doctor and literally what he said was ‘catch yourself on’. I actually went outside and stood then went back in again and I said to him, ‘look, ‘it’s alright for you, you’ve been to college and all the rest of it, you learned this and you have seen this… and he still dismissed me and I have never been back to him from then and I never got any help."

"He was 16 when he started on the antidepressants, he was 14 when he started cutting himself. The doctor told me and my husband that it was a phase, that he would grow out of it."

"I more or less told her I was suicidal and she left my house saying, 'I hope this is all tongue in cheek'. Now, I'll be honest, I got into my car the other day and in the back of my head is my kids but sometimes I just pray for that bus to hit me, things like that so it is over. It's not my fault but its things like that and it is as if these so called professionals would actually listen to the carers and take time out and listen to what is going on in their background. I don't know whether they could help or not but for someone to even sit and say, 'how are you?' and genuinely mean it, not go on with the next sentence."

"I think the thing is that doctors are happy enough to take the patients word for it rather than carry out a thorough assessment of the patients condition and are happy enough to let patients tick over."

"They do a year, up to July and then it changes again. That is only part of their training, they could end up being GPs, surgeons, whatever. That is probably whatever is happening, you can't actually blame that person because that person is away on somewhere else."

"He feels too that this is someone who doesn't care about him, because they are going to be moving on in a couple of months. What's the point when you are going through the same story all the time?"

"Same as what you are saying, when somebody new comes in and you meet someone new, you have to tell them the whole story over and over again and yet they have a file there, if they come to your house or they know that you are coming, why don't they look at your file?"

"It is starting from scratch each time and it's like you're first appointment each time."

"Your story gets abbreviated and abbreviated, it's not the real size, it gets shrunk down to suit who you are speaking to or you are so fed up so everything gets squashed in and the truth isn't getting to come out."

"Well, I have to say, my doctor has been the best person, you know, he's known my condition, more or less, for the time I've had it and if I walk through his door, he would know to look at me if I was ill. He's very easy to talk to if there is something that I need sorting out, he is very helpful. I don't particularly get that from the other doctors- it's just this particular one. He's always been very good with me and I think that's very important when you've got something that is long-term."

Getting Appointments

"I went to my doctor in July because I was going on holiday and I couldn't stop crying, I wasn't looking forward to it at all. She gave me a few Diazepam and told me it wasn't a psychiatrist I needed to see; it was a psychologist and that she would refer me to the Mater. I got a letter back from the Mater to say I was on a waiting list."

"They sent him to the psychiatrist, there was a waiting list obviously to get to see the psychiatrist, but he in fact, it was a psychologist he needed but there was no point in even putting him on the waiting list because it would be 2 years, so instead of seeing a psychologist, he was on the waiting list for a psychiatrist, even though he knew that a psychiatrist would be of no benefit to him he said ‘well, that’s better then nothing’. “

“Every time he went to see a psychiatrist it was a different person so there was no continuity and he felt like he was telling his story over and over again to different people and that wasn’t good for him and whenever he was saying that he was still feeling down, they would say ‘well we will up your dose then’. There is no review, that dose went up and has stayed up for a couple of years now. I keep saying to him, ‘what’s happening about these tablets?’ You can’t actually get to see the psychiatrist yourself to talk to them.”

Discharge

“He tried to commit suicide…they said to me ‘we can only go on what your husband says, not what you say’ and they said he was fit to leave and 3 days later he did it again…I actually said to the doctor, I was in tears talking to the doctor, ‘what am I going to do here, they keep sending him home and he keeps doing it again?’ They said, ‘well we have spoken to him and he has said that he is fine now and that he is sorry that he did it’. I said, ‘he was fine the other day when you let him out and you are still going to let him out again’…It’s like they have tick boxes, there’s questions or something and if he ticks certain boxes then he can go out…it’s like black and white.”

“Many times I have gone and I haven’t seen a psychiatrist, or they maybe have said, well there’s nobody there but we’ll phone you in the morning. I’m still waiting on a phone call. And that’s been said to me on at least two occasions.”

“When I went down I couldn’t get over the state that he was in. They let me bring him home and I didn’t know what to do with him or how I was going to cope with him. They asked me if I felt alright for J to go home and I said no as I have two wee kids at home and J’s behaviour is not right and they still let him home.”

Alcohol and Drugs

“The dual thing with the drink and the other problems. Doctors don’t seem to realise that they go hand in hand, they all say, once the drink seems to be a problem they don’t have the same sympathy.”

“I feel it should be treated hand in hand or something but you always get this thing that they should stop drinking first, that there is no point in us looking at the other problems until they stop drinking, but it is not as simple as that.”

“As you said yourself, they need to realise that the alcohol probably isn’t the real problem, it is like a symptom of it.”

“They won’t listen to the kids. What you are all saying about the drugs and all that too, they do put the drugs first, I have asked that many CPNs [Community Psychiatric Nurses] why they put the drugs before their illness. A lot of kids have got a mental illness first, then they turn to the drugs or they turn to the drink but they are not listening to what they are telling them and that is a very easy way out of it. They can wash their hands of you then, you won’t be their problem.”

Lack of Services

“Even the GPs don’t say to you where you can go. You have to search for these places for yourself.”

“We are reaching out for services that are supposed to be there on people’s behalf and they are just not there, there is nothing to grab onto.”

“I think it is about realising that people in crisis need to be treated by A&E and GPs, by dedicated staff who are trained in the field and have an expertise of mental health and addiction services. They need to treat people with respect and give them the same services as if I break my arm and I go along I can get a plaster of paris and have a turnaround in 2 or 3 hours and have it more or less sorted with a follow up appointment for an x-ray a week later or a check up. It just doesn't happen with mental health."

"The problem is too that there are not enough people out there to cope with the problem as well."

"He asked me all these questions which I knew throughout the years and you know, they'd asked me millions of times. At the end of it he says you have to come into the hospital, but, we've no beds. So, you know like, you really need to come in. It's like saying, you really need to come in for that heart operation but I'm sorry, but you're going to have to die of a heart attack, because, you know, we can't, you know, accommodate you."

"These signs I see, on television- if you're not feeling well; if you have a mental health problem- seek help. Look, I can assure you- I certainly don't find the help is there."

"I had reached a point where the different agencies have made me feel, well, if they don't think your life is precious, then why should we?"

Complaints

"I don't know why I just didn't [complain] when this all happened. I don't know why I let him speak to him the way that he did, I don't know why I let the girl tell me there was nothing wrong with him when I knew that there was. Under such and such act, she said to me, he's normal and .....I just thought, she is qualified."

"I think I feel, what would be the point?"

"What would be the reaction if I went and complained about something, what would happen?"

"We still need the services, would I get someone being a bit aggressive because I have complained about them not doing their work?"

"I have kind of complained, I told the team that I wasn't very happy with the way that they dealt with my husband's situation and that I didn't feel like that took on board my side of the fence. I wasn't nasty with them but I was getting a bit highly strung because I thought 'where is this going and why can you get nowhere?' She then became very aggressive back to me and said that they couldn't do anything, that they understand your point of view but we can't take anything you say into consideration, we are just dealing with your husband and that is it. We just have to go on what he says, we can't take what you say into account. I thought, what's the point?"

Appendix 4

Summary of Conference Evaluation Forms

1. What did you feel was the best aspect of this event?

A huge majority rated the inputs from PIPS/RAYS and other directly affected people as the best aspect of the event. Their participation and learned experience were very valuable to most of the attendees. The use of indicators, the specific targets identified and the practical application of a Human Rights Based Approach were also rated highly. Many people found the feedback from the international panel very useful. Sarah Hayden's (Headstrong presentation) inspired a number of attendees. The use of the DVD footage was also praised.

2. What did you feel was the worst aspect of this event?

Some people felt that there was too much information presented within a short period of time. However, conversely some others felt that more information would have improved the event. There were a number of comments on the lack of participation from the audience and the lack of decision-makers/ statutory agencies present. Time-keeping and the large number of people who left after lunch were also issues for a small number of attendees.

3. What were your expectations of this event and to what extent were they met?

A large majority of attendees commented that their expectations were met or exceeded. People had a range of expectations from learning about mental health issues generally, to benefiting from learned experience, to specific knowledge about indicators and measuring progressive realisation. Some people did not know what to expect but still felt they had learned some interesting and valuable from the speakers.

4. Have you been able to take anything from the event of use to you in your work?

Everyone who replied to this question felt that they could take something useful from the event to use in their work. This ranged from the need to look at how service users participate in decision making, to useful contacts made, to how to use baseline evidence and use indicators to measure change. The need to ensure meaningful participation for service users rather then tokenism was mentioned by a number of attendees.

5. How would you rate this event overall and how might it have been improved?

Overall a large majority rated the event highly with many attendees rating it as excellent or first class.

A number of people would have liked more participation from the floor. The lack of decision-makers present was commented on by a number of people who attended. One attendee felt it might have been useful to have a devil's advocate setting out the problems working in the mental health sphere.

6. Any other comments

All the speakers, particularly PIPS/RAYS, and organisers were thanked and congratulated for their work. The importance of raising the profile of mental health issues was stressed. Many attendees expressed their interest in following progress on the issues raised and seeing outcomes and improvements in mental health services.

Appendix 5

Conference Registration List

Janine Adams	RAYS
Karen Ashe	QUB Social Work Student & Unison Member
Orla Barron	Health & Inequalities Unit
Evan Bates	
Liz Beattie	Aware Defeat Depression
Janice Beggs	UNBCEP
Louise Beirne	Combat Poverty Agency
Dr Ephrem Bogues	
Patricia Boyd	Shankill Women's Centre
Roisin Brady-Moyes	
Sean Brown	EHSSC
Kate Browne	PIPS
Nicola Browne	PPR Project
Bronagh Byrne	Disability Action
Emma Caldwell	Social Work Student at QUB
Damien Cavanagh	CAUSE
Shelly Chambers	
Ashley Clemo	Queens University
Roberta Coates	RAYS
David Colvin	Epic Advice Centre
Tierna Cunningham	
Christian Courtis	International Commission of Jurists, Panel Member
Gladys Davenport	RNID
Gavin Davidson	Northern Health & Social Care Trust
Christina Davis	
Avril Dennison	PPR Project
Josephine Devlin	DHSSPS
Terry Enright	
Mary Enright	PPR Project Management Committee
Karin Eyben	Rural Community Network
Seamus Flynn	
Aideen Gilmore	Committee on the Administration of Justice
Phyllis Graham	
Stephanie Green	PPR Project
Fiona Green	Rethink
Jean Hand	PIPS/RAYS Rights Group
Colin Harper	Disability Action
Sarah Hayden	Headstrong, Speaker
Oonagh Kane	PPR Project
David Kane	

Joe Kelly	LAMP
Sandra Kirk	RAYS Crisis Centre
Michele Lamb	University of Essex
Michail Larkin	Acorn Centre
Margery Magee	N&W Belfast Health Action Zone
Caroline Maguire	Law Centre (NI)
Liz Main	Royal College of Psychiatrists
Olga Mason	
Liam McAnoy	Community Conventions Ltd
Maura McCallion	Law Centre (NI)
Gerard McCartan	PIPS
Carol McCartan	PIPS
Gary McClean	
Doris McClenaghan	LAMP
Gail McConnell	
Inez McCormack	PPR Project Chair
Francis McCracken	
John McGeown	Belfast HSC Trust
Janet McKay	PR Consultant
Orlagh McKearney	Opportunity Youth
Noel McKenna	Mental Health Commission for Northern Ireland
Patricia McKeown	President of Irish Congress of Trade Unions
Fiona McKibbin	
Pauline McMaster	RAYS Crisis Centre
Frank McMillan	PPR Project
Louise McNicholl	Human Rights Consortium
Sean McParland	Law Centre (NI)
Una McRoberts	Ardoyne/Shankill Healthy Living Centre
Danny McShane	East Belfast Community Development Agency
Monica McWilliams	Northern Ireland Human Rights Commission
Thomas Mehaffy	Unison
Prof Tara Melish	Visiting Professor at University of Georgia School of Law, Panel Member
Deborah Morgan	
Maria Morgan	Belfast HSC Trust
Therese Moriarty	
Fiona Murphy	Committee on the Administration of Justice
Enrica Murray	Social Work Student at QUB
Caroline Nelis	Social Work Student at QUB
Gabrielle Nellis	NHSSB
Maeve Ni Liatháin	PPR Project

Laura Niwa	Law Centre, Speaker
Trish O'Kane	Star Neighbourhood Centre
Camilla Parker	Mental Health & Human Rights Specialist, Panel Member
Anne Pendleton	BIFHE
Marie Quiery	
Roisin Quine	
Brenda Quinn	Belfast HSC Trust
Anne Rollins	RNID
Nuala Smith	Headstrong, Speaker
Rosemary Smith	Springboard
Nigel Spiers	Northern Health & Social Care Trust
Richard Summerville	Creative Media
Jonathon Swallow	Swallow Consulting
Karen Taylor	Irish Advocacy Network, Speaker
John Veitch	Belfast Health & Social Care Trust
Kathryn Vella	
Barbara Wensley	HMP Magilligan, Psychiatric Nurse
Margaret Woods	Renewing Communities, Mental Health Promotion