Submission to the Northern Ireland Human Rights Commission Inquiry into emergency health care

Introduction

The Participation and the Practice of Rights (PPR) organisation was established in 2006 by internationally renowned trade unionist and human rights activist Inez McCormack. PPR supports disadvantaged groups in Northern Ireland (NI) to make their socio-economic rights real and assert their right to participate in government decisions which affect their lives. PPR enables groups to challenge and change current government decision making practices which exclude them, and which lead to poor service delivery, entrenched inequalities and ineffective use of public money. To do this, PPR supports affected groups to use a human rights based approach (HRBA) to the economic and social issues that directly impact their lives.

PPR's human rights based approach was cited as a best practice example of 'how communities can claim their rights' by the United Nations Office of the High Commissioner for Human Rights in the 2012 publication "Human Rights Indicators: A Guide to Measurement and Implementation".[1] In November 2013, the Belfast Mental Health Rights Group (our longest established mental health group) was jointly awarded the inaugural Steve Pittam Social Justice award.

Since 2006, PPR have been working with mental health service users, carers and families bereaved by suicide in the Belfast area on issues relating to the implementation of the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12 right to the highest attainable standard of health.

Accessing mental health care at an emergency setting;

It is significant that despite the expansion of this work, from its early beginnings with a small group in North Belfast in 2006 as the PIPS/RAYS Rights Group, to wider membership encompassing all areas of the city in 2010 as the Belfast Mental Health Rights Group; core concerns around the access to mental health care at Accident and Emergency Departments have remained. Indeed, in March 2014 we launched the research of the new expanded Mental Health Rights Campaign (involving groups across Northern Ireland including in Cookstown, Draperstown and Newcastle)[2] which continued to identify problems with emergency health care as a priority issue. Throughout this paper, the work of each of these groups is referred to. For clarity, all of these groups are entirely comprised of mental health service users, carers and families bereaved through suicide who are using PPR's human rights based approach to achieve change.

PPR wish to underline at the outset a fundamental and often overlooked determination regarding the use of emergency care in Northern Ireland. Our work in areas such as North and West Belfast, areas of high deprivation and correspondingly high suicide rates, has

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[1] For further, please see http://www.ohchr.org/EN/NewsEvents/Pages/IndicatorsessentialtoolsinrealizationofHR.aspx

[2] Please see Mental Health Rights Campaign (March 2014) 'Time to Listen; Time to Act; Holding Mental Health Services to Account' report available at http://pprproject.org/sites/default/files/Time%20to%20Listen%20publication%20compressed.pdf

identified that people in these communities access health care from emergency health care settings at a higher rate than those who live in less deprived areas. This understanding is supported by Belfast Health and Social Care Trust research entitled "A report on patterns and trends in the use of hospital services in Northern Ireland." This Northern Ireland wide research, published in 2008, analysed patterns and trends in the use of certain hospital services during the period 1998/1990 and 2006/2007, taking account of geographical area, age, gender and economic deprivation. It concluded that deprived communities disproportionately access health service through an A&E setting whereas their more affluent neighbours are more likely to access healthcare provision through GPs.[3]

It has therefore been our experience that poor service delivery outcomes at emergency care settings can have a discriminatory impact on people who live in deprived communities for whom health care is disproportionately accessed at an emergency care or A&E setting.

Key issues:

PPR's work with the Belfast Mental Health Rights Group and others has identified serious and systemic problems with mental health service design and delivery at A&E settings in Northern Ireland which have consistently failed the most vulnerable. In our annual surveys, focus groups, workshops and interviews conducted with mental health service users and carers or someone who has attended A&E with them, the key problems include insufficient access to information about their care, excessive waiting times and problems around follow up care following discharge from A&E. The group has set human right indicators to monitor progress on each of these issues and to ascertain if their right to health is being realised on the ground. Each of these areas are examined in turn below.

Information:

Despite the UNESCR Committee's observations that the right to health requires the State to fulfil obligations which include *"supporting people in making informed choices about their health"*[4] significant failures remain in ensuring people have enough and the right type of information to make decisions about their care.

The baseline results (March 2014) for the Mental Health Rights Campaign human rights indicator on this issue for example identifies that only 9% of mental health patients and carers told us there was enough information about where to go to get help when in mental health distress,[5]

Information is also critical when in A&E and following discharge. As one mental health service user told us information at A&E was critical *"not so much for myself, but for my partner or whoever was with me, for them to know what to do next"*. In 2010, only 20% of those who took part in our research told us that they were happy with the level of information they received about their treatment and the care pathway. By 2011, this had increased

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[3] Belfast Health and Social Care Trust (2008) "A report on patterns and trends in the use of hospital services in Northern Ireland."

[4] United Nations Committee on Economic Social and Cultural Rights (UNCESCR) General Comment 14, paragraph 37

[5] http://pprproject.org/sites/default/files/Time%20to%20Listen%20publication%20compressed.pdf p.13-15

slightly to 29% but was still well below the human rights benchmark the BMHRG had set at 85%.[6]

Waiting times:

The UNESCR Committee have clearly determined that the right to health requires that care is both *"timely and appropriate"*[7]*.* Despite this however, accessing mental health care at emergency settings in Northern Ireland often involves lengthy delays.

In 2011 for example, 46% of people who took part in our research told us that they waited over the four hour standard set by the Department of Health, to be seen by a doctor in one of Belfast's Emergency Departments. This represented almost no change on similar research carried out the year before, which recorded 45% waiting over four hours.[8]

By March 2014, 66% of those who took part in our research following an attendance at A&E viewed the waiting time as unsatisfactory or very unsatisfactory[9]

Follow up care:

One of the first issues the Belfast Mental Health Rights Group campaigned on was getting appropriate and timely follow up care for patients in mental health crisis when discharged from A&E. As Grace Cassidy, a carer and member of the Belfast Mental Health Rights Group stated, ***"****People need and deserve proper follow up care so they don't get into crisis again. Without it, things become a vicious cycle."* Research also shows that this is a time when patients are at higher risk of taking their own lives.

Despite the clear emphasis in international human rights law on the requirement for timely and appropriate access to health care and the need for individually prescribed care plans[10] research carried out in the last five years has highlighted problems in this regard. In 2009, research carried out by the PIPS/RAYS Rights Group identified that only 13% of those leaving A&E received a follow up appointment[11] The situation had not changed by 2010, with only 13% of those taking part in the Belfast Mental Health Rights Group's research stating that on discharge from A&E they had received a follow up appointment. By 2011, similar

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[6] http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf p.8-10

[7] United Nations Committee on Economic Social and Cultural Rights (UNCESCR) General Comment 14, paragraph 11

[8] For further please see http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf

[9] Please see Mental Health Rights Campaign (March 2014) 'Time to Listen; Time to Act; Holding Mental Health Services to Account' report available at http://pprproject.org/sites/default/files/Time%20to%20Listen%20publication%20compressed.pdf

[10] For example, please see Principles for the protection of persons with mental illness and the improvement of mental health care', Adopted by the General Assembly resolution 4/119 of 17 December 1991, Principle 9(2) which states;

> *"The treatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualifies professional staff".*

[11] See http://issuu.com/ppr-org/docs/rights_in_action_mental__health__forum__report_28_ p.27

research showed that the number had risen slightly to 15%[12] but the majority were still 'slipping through the cracks'. March 2014 research carried out by the expanded Mental Health Rights Campaign reiterated the continued importance of this issue at emergency care settings with not a single person who took part in the research having received a follow up appointment following an attendance at A&E when in mental health crisis.[13]

Participation:

PPR's work with mental health service users and carers has also identified that at the core of the problems with service delivery outcomes at emergency healthcare settings is an ineffective government decision making process which does not prioritise the concerns of rights holders since their meaningful participation in decision making around policy/programmes is often not facilitated.

Despite international human rights law making clear the obligation on the State to ensure meaningful involvement of service users in government decision making[14] and statutory requirements in this regard[15], mental health service users accessing health care at A&E's have consistently told us that this participation is not meaningful.

Our "Services at Breaking Point" research carried out by the BMHRG identified that of those patients and their carers who attended A&E in mental health distress in 2010, 10% stated that that they felt involved in decisions made about mental health services in Northern Ireland. By 2011, despite the launch of revised strategies for involvement by the Public Health Agency and the Health and Social Care Board, the number of survey respondents who indicated that they felt involved in decisions made about mental health services in Northern Ireland plummeted to 0%.[16]Similar recent research (March 2014) carried out by the Mental Health Rights Campaign identified that this problem continues to persist with only 3% of those who took part in the research stating that they feel involved in decisions government make about mental health services, including those provided at emergency care settings[17].

Case Study: Realising the right to participation: Card Before You Leave

The Card Before You Leave appointment card system was launched by the then Health Minister Michael McGimpsey in 2010. This scheme enabled patients who were considered

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[12] See p.14-16 http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf

[13] See p.10-12 http://pprproject.org/sites/default/files/Time%20to%20Listen%20publication%20compressed.pdf

[14] For example, see United Nations Committee on Economic Social and Cultural Rights (UNCESCR) General Comment 14, paragraph 37

[15] For example, under the Health and Social Care (Reform) Northern Ireland Act 2009, HSC organisations have a statutory requirement to involve service users, carers and the public in the planning, commissioning, delivery and evaluation of services.

[16] See p.18-19 http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf

[17] See p.16-17 http://pprproject.org/sites/default/files/Time%20to%20Listen%20publication%20compressed.pdf

‘low risk’ and who didn’t require admission to be discharged from A&E with an appointment card which gave details of the date and time of their follow up appointment to receive a full mental health assessment within 24 hours. The scheme was the result of a concerted campaign by the Belfast Mental Health Rights Group and others for a ‘lifeline’ following concerns that people in mental health distress were being discharged from A&E with no support or follow up care[18].Following the official launch of the scheme,the group realised that securing a commitment to implement change was not enough – the change had to be working on the ground helping those most vulnerable patients using A&E when in mental crisis. For this reason, the group continued with their campaign to ensure the new scheme was implemented properly. They did this by continuous monitoring of patient and carer experience at A&E through surveys and focus groups and by participating in the Card Before You Leave Implementation Board which was set up by the Northern Ireland Health and Social Care Board.

The group recognised from their own experiences that only real and meaningful participation on the Card Before You Leave Implementation Board would bring about real change on the ground for patients. So, to ensure this they monitored how meaningful their participation was at meetings. This was done through the use of participation indicators based on international human rights standards which they developed with PPR’s support.

Participation indicators

Based on their previous experience on consultative structures, BMHRG identified barriers to participation before the meeting; during the meeting and in general. They wished to overcome these and ensure that steps were taken to progressively realise their right to health and that they were able to participate meaningfully in decisions made by the Board. Consequently, the following human rights based participation indicators were set in 2010.

Before the meeting	• We had the date, time, location and agenda two weeks in advance • We had the opportunity to place items on the agenda and have them considered in a timely manner
During the meeting	• The language used was jargon free • Any information which was presented was in writing so we can discuss it with the rest of the group
In general	• Any disagreements were resolved at the meeting effectively

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[18] For further information on the Card Before You Leave campaign please see the Story of the Card Before You Leave campaign

	• Our expenses were covered

Despite the international human rights obligations on the State, the fact that the indicators were written into the Terms of Reference of the Board and the relatively simple nature of the 'asks', the results of the BMHRG's monitoring demonstrated key failings in the Board's progressive realisation of these indicators. For example, between April 2010 and May 2011, the agenda was never sent out two weeks in advance of the meetings, on average it was sent two days before the meeting which made it difficult for the BMHRG to adequately prepare.[19]

It was on the basis of the concrete evidence of the failings of the Card Before You Leave Board to meet the participation standards that senior officials within the Health and Social Care Board immediately requested a meeting with the Group. During this meeting, senior officials commented that it was "useful" to have the participation standards since they clearly indicated what the Board could do to improve participation as well as indicating that they felt the issues could be "easily resolved". In the aftermath of this meeting the Card Before You Leave Board arranged for a dedicated member of staff to ensure that the participation standards are being met.

Key lessons

By measuring how well or how poorly the Board met the standards, the Group gathered evidence on how poor participation was leading to poor decision making. The evidence shows that there is a direct correlation between participation, decision making and outcomes on the ground for people who use services. The use of the participation indicators to effectively monitor and ensure the realisation of meaningful participation enabled the group to ensure that the Card Before You Leave was exactly that not for example, a phone call, which was something that some Trusts tried to implement. The group's involvement also led to the adoption of a duplicate card for carers and family of a patient. The Card Before You Leave scheme was successfully evaluated in April 2013 with a number of recommendations being made to improve patient experience at A&E.[20]

In 2013 the Project Board meetings at which the group used the participation indicators ceased to meet and responsibility for implementation of Card Before You Leave was transferred to the HSCB's Self Harm Working Group. The group continue to use these standards as the basis of rights based participative engagement with this body, and monitor their performance.

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[19] For further on the BMHRG's monitoring please see p.23-26 http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf

[20] HSC (April 2013) Evaluation of the operation and effectiveness of the "Card Before You Leave" scheme in the context of other suicide prevention initiatives within Northern Ireland available at http://www.hscboard.hscni.net/publications/2013/20130425%20Card%20before%20you%20leave%20scheme%20-%20Evaluation%20-%20PDF%20635KB.pdf

Problems remain with the implementation of the appointment system as outlined above (see section on Follow Up care) however the group continue to campaign to ensure Card Before You Leave reaches all those who need it.

PPR and the BMHRG would recommend to the NIHRC Inquiry further consideration of the human rights participation indicators model used in the implementation of Card Before You Leave as a model of good practice.

Current issue of concern:

The Card Before You Leave Campaign, as well as our monitoring over the last five years has also opened up other issues about patient and carer experience at A&E. As discussed above, one issue that repeatedly came up in surveys was that there is not enough information for patients and carers at A&E about the patient's treatment. Recently, the BMHRG became aware that there is a Family Guide called *'Caring for someone who has self-harmed or had suicidal thoughts'* which is supposed to be given out at A&E and GP surgeries. BMHRG are concerned that the guide in its current format does not contain the right type of information in the most appropriate format to adequately support families supporting a loved one in mental health crisis. A key concern of families for example, is that information regarding sectioning for example is entirely absent from the publication and one carer commented that the booklet is much too long to read in such a stressful A&E environment. Following contact with a number of voluntary and community organisations which provide support for people in mental health crisis, BMHRG are additionally concerned that despite the resources involved in producing, publishing and supplying the booklet, most groups they spoke with were not aware of anyone receiving the booklet.

PPR and the Mental Health Rights Campaign groups would recommend the NIHRC Inquiry consider highlighting the importance of accessible, informative and relevant information being made available to patients and their families/carers in an emergency care setting about treatment options and follow up care. PPR and BMHRG would further recommend that the NIHRC Inquiry recommendations stress that such information should be designed and produced with the meaningful involvement of patients and their carers/families with whom valuable expertise as to the need for such information lies.

Resources enclosed:

(2014) Mental Health Rights Campaign research, *Time to Listen, Time to Act; Holding Mental Health Services to Account*
(2012) Belfast Mental Health Rights Group research, *Services at Breaking Point; Fighting to Have Our Voices Heard*
(2013) PPR consultation response, HSC Transforming Your Care; A Vision to Action[21]
(2013) PPR consultation response, HSC Board Proposed Future Configuration of Emergency Departments in Belfast [22]

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[21] http://pprproject.org/sites/default/files/PPR%20response%20Transforming%20Your%20Care%2015012013.pdf

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[22] http://pprproject.org/sites/default/files/PPR%20response%20to%20Proposed%20Future%20Configuration%20of%20Emergency%20Departments%20in%20Belfast.pdf