

# **PIPS-GREATER SHANKILL BEREAVED FAMILIES RIGHTS**

## **GROUP**

### **First Report on the Progress of Human Rights Indicators**

**September 2008**

#### **1. Introduction**

- 1.1 The PIPS-Greater Shankill Bereaved Families Rights Group is made up of individuals who have either been bereaved through suicide or who have a member of their family suffering from serious mental illness. **They use a human rights based approach to advocate for changes to access to and delivery of mental health services in Northern Ireland.**
- 1.2 The changes the group advocates were identified through a development programme with the Participation and the Practice of Rights Project (PPR). They identified a broad set of issues regarding mental health services in Northern Ireland that needed to be improved. After linking many of these issues to international human rights and local policy standards, to ensure that they pursued change on the strongest and most pressing of them, the group then carried out surveys to assess the extent to which of these issues affected other mental health service users.
- 1.3 Human rights standards require government to ‘progressively realise’ people’s economic and social rights – i.e., the standards require that services get better over time. Accordingly, the group set human rights indicators and benchmarks for change that measure, both, whether services are actually getting better, and whether the human right to the highest attainable standard of mental health is being achieved.

- 1.4 **The group presented these human rights indicators and the results of their surveys to an International Panel of human rights and mental health experts in November 2007. The panel validated the human rights indicators advocated by the group as a reasonable and necessary timeline for change.** The panel's findings were published with the group's human rights indicators in the 'Findings and Recommendations of the International Panel,' launched on 26<sup>th</sup> February 2008.
- 1.5 The results contained in this report detail the experiences of 50 mental health service users who have been in contact with mental health services at GP or hospital level since November 2007. The group imposed this time limit both to ensure that the group only collected data from those who had used mental health services since the baseline measurement in November 2007 and to gauge more accurately the progress or retrogression that had occurred since that original measurement. The group collected the surveys through a broad network of members of organisations including Aware, Ardoyne-Shankill Health Living Centre, Greater Shankill Bereaved Families, PIPS, Shankill Women's Centre, Upper North Belfast CEP, and others. The majority of the mental health service users surveyed had used services in North Belfast. Around half of those surveyed had accessed services in hospital and all had visited their GP regarding a mental health problem.
- 1.6 **This Progress Report details the results of this first monitoring of the group's human rights indicators since the baseline measurement in November 2007.** The group delayed the first monitoring period from the original six-month timeline to September 2008 at the request of the

Belfast Health and Social Care Trust to give them an opportunity to respond to the findings.

## 2. Progress To Date

### *Follow Up Appointments*

- 2.1 A timely follow up appointment after discharge from hospital represents a lifeline for mental health patients contemplating suicide or self harm. **Statistics from the Department of Health in the UK support this claim with 66% of post-hospital-discharge suicides in Northern Ireland occurring before the first follow-up appointment.**<sup>i</sup>
- 2.2 Local and international human rights policy sets specific standards in relation to follow-up appointments. NHS Guidelines require that people discharged from hospital with severe mental illness or who are at risk of deliberate self-harm be seen at a follow-up appointment within a week.<sup>ii</sup> International human rights law also requires “timely access to...mental health treatment and care”<sup>iii</sup> and states that the “absence of an effective referral system is inconsistent with the right to the highest attainable standard of health”.<sup>iv</sup>

### **Human Rights Indicator**

The group’s indicator regarding follow-up appointments for mental health patients was that, in six months, 45% should receive a follow-up appointment within a week. This indicator was endorsed by an international panel of mental health and human rights experts in November 2007 as a reasonable and necessary timeline for change.

The group’s monitoring in September 2008, however, has shown:

- Only 13% of mental health patients received a follow up appointment within a week.
- 71% of patients had to wait a month or longer before they attended a follow up appointment.

**This shows no change from the baseline results in November 2007, when 13% of mental health patients received a follow up appointment within a week.**

2.3 In a response to the findings of the International Panel, the Belfast Health and Social Care Trust has stated (and the Department of Health has confirmed) that a ‘Card Before You Leave’ appointment system has been implemented in Belfast Trust Hospitals from the 1<sup>st</sup> August 2008 as an interim measure. Discussions will be held between the Belfast Trust and the DHSSPS about the system’s implementation throughout Northern Ireland in mid-October.

### **Urgent Actions Required**

**The next step** is for the group to participate in the audit of this policy to be carried out in November by the Belfast Trust in a manner compatible with the international panels’ findings on participation. to ensure that the standards for participation set out in the findings are realised. It is essential to monitor the number of patients receiving a ‘Card Before You Leave’, the number of patients excluded from the appointment system and the rationale for this decision. It is vital that the Trust monitor when the patients **were actually seen** at their follow up appointment in order to assess whether the relevant NHS standard is being met. This will help ensure the system effectively serves the needs of mental health service users both in Belfast and across Northern Ireland.



*Rhonda Hill and Gerard McCartan of the PIPS-Greater Shankill Bereaved Families Rights Group at the Launch of the ‘Card Before You Leave’ Appointment System Campaign.*

## *Complaints*

2.4 An effective hospital complaints system provides invaluable information about the state of health services. It offers recommendations for how one can redirect resources both to better satisfy patients and to spend money more efficiently. It should offer effective and speedy redress for problems encountered.

2.5 Local and international human rights policy sets specific standards in relation to complaints in a health system. Local guidance states that service users should be “made aware of their right to complain and given the opportunity to understand all possible options for pursuing a complaint.”<sup>v</sup> International human rights law states that patients are entitled to an “accessible, affordable, timely and effective” remedy like a complaints system.<sup>vi</sup>

### **Human Rights Indicator**

The group’s indicator regarding the complaints system was that, in 6 months, 45% of dissatisfied mental health patients should access the complaints system. This indicator was endorsed by an international panel of mental health and human rights experts in November 2007 as a reasonable and necessary timeline for change.

The group’s monitoring in September 2008, however, has shown:

- Only 14% of dissatisfied mental health patients accessed the complaints system.

**This shows significant retrogression from the baseline results in November 2007, when 31% of dissatisfied mental health patients accessed the complaints svstem.**

2.6 In summer 2007, the group made a submission to the government's review of complaints. The government plans to implement the new complaints system on the 1<sup>st</sup> of April 2009.

### **Urgent Actions Required**

- **The next step** is for the government to assess how the proposed new complaints system will fulfil international human rights standards for an “accessible, affordable, timely and effective” remedy. An effective monitoring system must also be created to ensure that this standard is maintained. This is vital in light of the fact that 50% of respondents not making a complaint did not know how to access the complaints system and 40% believed it would not make a difference even if they did.
- **Additionally, there must immediately be** an effective interim system to allow more than merely 14% of dissatisfied users to access the complaints system. Thus far, the Belfast Trust has had difficulty placing a permanent, visible poster about the complaints system in the Mater Hospital's A&E waiting room. If this simple step cannot happen, the group is concerned about the Trust's ability to implement effective long- and short-term solutions.



*Members of the International Panel of Human Rights and Mental Health Experts, Christian Courtis, Prof. Tara Melish and Camilla Parker with PPR Project Chair Inez McCormack*

## *Information from GPs*

- 2.7 Lack of knowledge both about the symptoms and effects of mental illness as well as about potential side effects of medication has had devastating results for patients and families. Information allows patients and families to know what to expect and to prepare for potential consequences.
- 2.8 Local and international human rights policy sets specific standards in relation to the information GPs provide to mental health patients. *Protect Life*, Northern Ireland's suicide prevention strategy, makes suicide awareness and prevention a priority for all "front line health service staff."<sup>vii</sup> Other policies require development and delivery of Depression Awareness Training for GPs.<sup>viii</sup> The International Panel of mental health and human rights experts found that the Minister for Health should take 'decisive action to ensure that all general practitioners do take the required training course'. International human rights law requires that information be accessible to patients in order to improve services.<sup>ix</sup>

### **Human Rights Indicator**

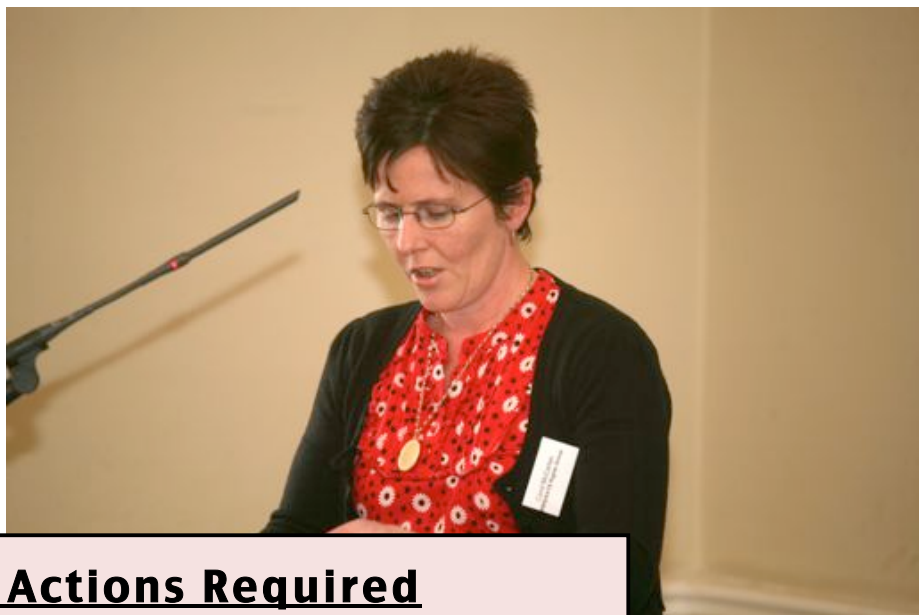
The first indicator the group set regarding the information provided by GPs was, in 6 months, 45% of patients should be satisfied with information provided *about mental health conditions*. The second indicator was, in 6 months, 50% of patients should be satisfied with information *about prescribed medication*. Both indicators were endorsed by an international panel of mental health and human rights experts in November 2007 as reasonable and necessary timelines for change.

The group's monitoring in September 2008 has shown:

- 52% of mental health patients were satisfied with information provided by GPs about mental health conditions;
- 38% of mental health patients were satisfied with information provided by GPs about medication prescribed.

**Thus, the government has met one indicator and seen no change on the second indicator regarding information about prescribed medication.** In November 2007, 36% were satisfied with information about mental health conditions, 38% were satisfied with information about prescribed medication.

2.9 Government have set a target of achieving a 15% reduction in suicide by 2011. The Bamford Review's emphasis on developing primary care staff skills in the area of mental health to ensure most people can be treated at home is a laudable aim but is envisaged to take place over a 10-15 year time scale. In addition, the Department is working to implement training for new GPs on broad-spectrum mental health conditions.



### **Urgent Actions Required**

Given the long-term nature of the changes associated with the Bamford Review, it is essential that an interim measure be put in place to address the issue of GP training. The next steps, in line with international human rights standards, are

- That it be mandatory for all GPs to undertake training about broad-spectrum mental health conditions, so that there is not an inconsistency in provision between GPs who have recently been trained and those who have been practising for years. International standards are unequivocal in stating that appropriate training for health personnel is of comparable priority to a minimum core obligation on government. (Article 44 (e), General Comment No. 14 on the right to the highest attainable standard of health.)
- That mental health service users be directly involved in monitoring the training's content and effectiveness.

*Carol McCartan  
speaking on behalf of  
the PIPS-Greater  
Shankill Bereaved  
Families Rights Group  
at an event.*

## *Participation*

- 2.10 Meaningful involvement of mental health service users in decisions about the planning, implementation and review of mental health services is critical to ensuring the effective and efficient use of public resources. This is key to the standard of participation required by international and local human rights law and policy.
- 2.11 Local and international human rights policy sets specific standards in relation to the participation of mental health service users in decision-making about services that affect them. Northern Ireland's suicide prevention strategy, *Protect Life*, identifies participation and engagement with mental health service users as a guiding principle.<sup>x</sup> Furthermore, the Bamford Review is unequivocal in its commitment to ensure mental health service users are at the heart of the design and evaluation of services. International human rights law requires people affected by decisions to be involved in "setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health."<sup>xi</sup>

### **Human Rights Indicator**

The group's indicator regarding participation of mental health service users in government decision-making was that, in 6 months, 35% of those surveyed would rate themselves as involved. This indicator was endorsed by an international panel of mental health and human rights experts in November 2007 as a reasonable and necessary timeline for change.

The group's monitoring in September 2008, however, has shown:

- Only 20% of mental health service users felt involved in decision-making.

**This shows retrogression from the baseline results in November 2007, when 21% of mental health service users felt involved in decision-making.**

2.12 In November 2007, the International Panel of mental health and human rights experts recommended opening dialogue between the government and the group as a first step towards facilitating “active, free and meaningful” participation. The minister’s appointment of a senior departmental liaison for the group has begun this process of dialogue and accountability.



*Members of the PIPS-Greater Shankill Bereaved Families Rights Group being recognised for their work by Mary Robinson, Former UN High Commissioner for Human Rights.*

### **Urgent Actions Required**

The next step is to show how the process of dialogue and accountability set up by Minister McGimpsey might be developed into a model of good practice. This would enable government to prioritise the issues most important to mental health service users by involving them “actively, freely and meaningfully” in the decision-making process – as required by human rights standards.

The approach has already produced information showing the ways the system is not working and how public resources could be spent more efficiently. It has set reasonable indicators for change and brought about the implementation of a ‘Card Before You Leave’ appointment system for mental health patients. The ability of this work to highlight the small, meaningful changes that are both within government’s ability to achieve quickly and low cost is testament to the value of meaningful participation.

### 3. Conclusion

3.1 These results are of serious concern particularly as there has been retrogression on or no change in 4 of the 5 human rights indicators described in this report. The results of the monitoring of these indicators can be summarised as follows:

	Follow Up Appt. within a week	Dissatisfied users who accessed complaints system	Satisfaction with info. from GPs about mental health conditions	Satisfaction with info. from GPs about medication prescribed	Feel Involved in Decision-making about services
<b>Baseline Survey (November 2007)</b>	13%	31%	36%	38%	21%
<b>First Monitoring (September 2008)</b>	13%	14%	52%	38%	20%
<b>Change</b>	<b>None</b>	<b>-17%</b>	<b>+16%</b>	<b>None</b>	<b>-1%</b>

3.2 We need consistent and effective implementation of the urgent actions described in this report. This must occur through meaningful partnership between government and mental health service users based on human rights and equality standards. For example, although the Belfast Trust is implementing the ‘card before you leave’ appointment system and the group welcomes this – this now needs to be rolled out regionally without delay. Above all, unless service users are meaningfully and fully involved in accordance with international human rights standards for active, free and meaningful participation in the monitoring and evaluation of the system’s effectiveness, the government risks more resources being wasted and lives being lost.

3.3 Participation is the key link in the chain. It can ensure that best value solutions are devised for embedded problems, and that those solutions are

in turn implemented in the most effective way. By involving mental health service users directly through a standard of participation based on human rights standards, mental health service users were able to prioritise the issues most important to them for government. The Northern Ireland Health Committee in turn identified the ‘Card Before You Leave’ appointment system as one of its key recommendations to the Department of Health; the Minister for Health has agreed to implement this system across Northern Ireland by April 2009. From this evidence and from the reasonable and necessary actions outlined in this report, one can see both the value that a human rights based approach brings government and the respect it offers mental health service users. The power of participation speaks for itself.

3.4 The group will monitor these indicators again over the next six months.

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<sup>i</sup> *Safety First: Report of the National Confidential Inquiry Into Suicide And Homicide By People With Mental Illness*, Department of Health, 2001.

<sup>ii</sup> Recommendation from *Safety First: Report of the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness*, Dept of Health, United Kingdom, 2001 (“All discharged patients who have severe mental illness or a recent (less than three months) history of deliberate self-harm should be followed up within one week.”)

<sup>iii</sup> General Comment 14, para. 17, *UN Committee on Economic, Social and Cultural Rights*.

<sup>iv</sup> Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, A/HRC/7/11, 31 January 2008

<sup>v</sup> *Complaints in the Health and Personal Social Services, A Consultation Paper, November 2006*.

<sup>vi</sup> General Comment 14, para. 59, *UN Committee on Economic, Social and Cultural Rights*.

<sup>vii</sup> *Protect Life: A Shared Vision, The Northern Ireland Suicide Prevention Strategy and Action Plan, 2006-2011*.

<sup>viii</sup> *Promoting Mental Health Strategy and Action Plan, 2003-2008*, Chapter 3.

<sup>ix</sup> General Comment 14, para. 12(b), *UN Committee on Economic, Social and Cultural Rights*.

<sup>x</sup> *Protect Life: A Shared Vision, The Northern Ireland Suicide Prevention Strategy and Action Plan, 2006-2011*.

<sup>xi</sup> General Comment 14, para. 54, *UN Committee on Economic, Social and Cultural Rights*.