

From Pillar to Post:

The Card Before You Leave Campaign

“Why not give somebody an appointment card? Why wait on a letter that doesn’t arrive? Give them a wee card and tell them you will be seen on *this date*, at *this time*, on *this day*... because that’s a lifeline, a lifeline to the carers and a lifeline to the patient themselves.”

Gerard McCartan, PIPS /GSBF Rights Group¹

The proposal to introduce a Card Before You Leave (CBYL) appointment system was first made to government in 2005 as part of the independent review into the death of Danny McCartan. No action was taken on the proposal. During the years 2005-2009 a small group of bereaved families and mental health service users (PIPS/Greater Shankill Bereaved Families Rights Group) have worked for a commitment to, and implementation of a small service change which would save lives. Despite initial statements from the Belfast Trust that such a change would be impossible, and the Department’s position that no changes would be made to appointment systems, the CBYL appointment system is now being implemented across Northern Ireland.

In May 2009, the group held an event ‘From Pillar to Post: Linking Meaningful Participation to Improved Service Delivery’ in the Long Gallery at Stormont, to extract learning from the long and sometime frustrating journey they had been on while trying to ensure that one small change backed by statistical evidence, government, international experts, and service users became a reality.

This is the story of their campaign.

¹ Quote taken from Interview with Gerard as part of ‘From Pillar to Post: Linking Meaningful Participation and Mental Health Services’ video accessible online at <http://www.youtube.com/profile?user=PPRProject#p/u/4/5SqTi4-Agss>

APRIL 2006

In April 2006, members of two suicide/self harm support groups in North and West Belfast came together to discuss the increasing suicide rates in their areas. It was during this exchange that the issue of appointments first came up when several members recounted experiences of expecting follow up appointments for themselves and their family members which never arrived. The group also discussed how they were often asked to be *'involved'* in decision-making bodies, but that it often required them only to tell their personal stories, rather than allowing them to assist in how services were being delivered.

OCTOBER 2006

In October 2006 the group took part in a development programme with the Participation and the Practice of Rights Project, who work to support communities and groups in North Belfast in using a human rights based approach to tackling inequalities and deprivation. The members named themselves the PIPS / Greater Shankill Bereaved Families (PIPS/GSBF) Rights Group.

Following the development programme the groups selected a number of issues they wished to campaign on to achieve change. These issues, while local, were linked to international human rights standards that government had promised to make real over time. The issues were: follow up appointments, the complaints system and information from GPs on mental health issues. They also decided to measure whether government was enabling people to participate meaningfully in the decisions made in the delivery of their health services, as this was also required under human rights law. Their work began by measuring if government was actually making improvements on any of the issues they had selected.

NOVEMBER
2007

In November 2007 the PIPS/GSBF Rights Groups presented their work to a panel of international human rights and health experts in Belfast, including Professor Tara Melish, University of Georgia, USA; Christian Curtis, International Commission of Jurists, Geneva; and Camilla Parker, Mental Health and Human Rights Specialist. The panel endorsed the group's work and recommended that a Card Before You Leave appointment system for mental health patients be put in place as quickly as possible.

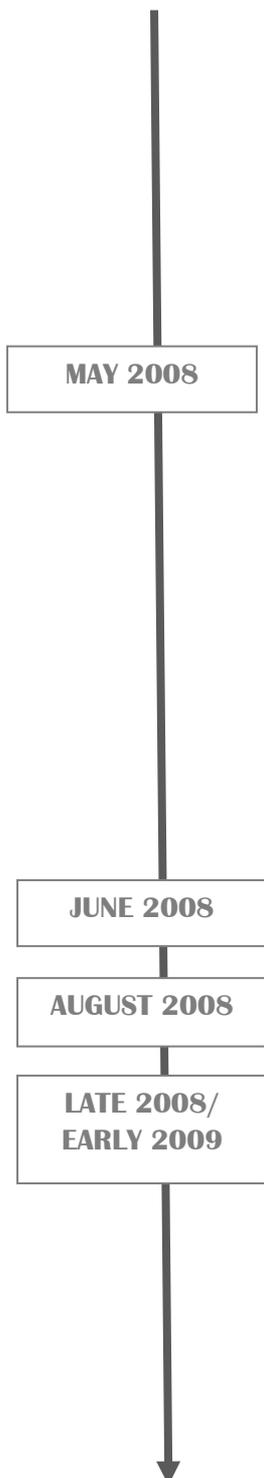
APRIL 2007

"It's only through people being involved in active and informed decision making or the setting of indicators that rights can move from an abstract level or something that's a reality on the ground- even though it may be a long and difficult process"

Helen Potts, at the 'Pillar to Post' event in May 2009

The Card Before You Leave campaign

Focussing specifically on the first indicator, based on follow up appointments, the group initiated a campaign for what they felt would be a 'lifeline' - that all those who were discharged from a hospital with serious mental health and self harm



problems would receive an appointment card before they left, thus maintaining their link with services. The Card Before You Leave (CBYL) Campaign was born.

Throughout the campaign, the group made repeated and sustained efforts to bring their work to the attention of government and service delivery bodies.

Two group members, Gerard and Roberta gave oral evidence to the Health Committee as part of their Inquiry into Suicide/Self Harm, detailing the CBYL campaign. The group also made a written submission. The group enlisted the help of other organisations such as the Law Centre NI and CAJ, and together lobbied local MLAs on the Committee. These interventions produced a result- the Committee's report of May 2008 made 24 recommendations, one of which was that the Card Before You Leave appointments system be implemented.

CBYL Campaign provoked the group to write to other agencies with responsibility on the issue, namely the Belfast Trust and the Minister for Health, lobbying them for their support. The group met with the Belfast Trust, the Health Trust responsible for the delivery of mental health services in their area, who were sympathetic to the group's plight but stated that the different IT systems in place to handle appointments across the Trusts could not be changed to provide a Card Before you Leave system.

Six weeks later on 17th June 2008, the group met with Michael McGimpsey, the Minister for Health, and an agreement to implement CBYL by April 2009 was reached. This was confirmed in writing in August 2008.

During the meeting with the Minister, a liaison officer was appointed between the Department of Health and the group to explore how all their issues could be taken forward. Pursuing the other indicators chosen by the group was to prove as taxing as the first. Throughout autumn 2008 and the early months of 2009, the group held meetings with various government and statutory officials and the Health promotion Agency around the issues of complaints and GP training as well as meetings on follow up appointments.

This constant procession of meeting after meeting had a draining impact on the group who felt like they were being pushed from pillar to post trying to make their voices heard and their stories translate into meaningful change, which they found to be difficult to translate into the regimented format of meetings- something which Dr. Helen Potts elaborated on.

A person's personal experience which is so essential to developing policy will be important to the extent that it's relevant to the discussion at that time...Those stories are really valid. And often you'll find that in institutional mechanisms that if the second part of the story is not relevant to the current decision making it will not necessarily be treated as valid."

Helen Potts at the 'Pillar to Post' event in May 2009

Through the process of meetings, the group learned that a Card Before You Leave Implementation Board was to be established. Following an enquiry to the board as to the extent of service user involvement on the Board, the group were notified that a service user from Co. Down had been asked to join the board rather than a member of the group who had campaigned for the change and built up expertise on it. The group felt that their participation in the implementation process of the CBYL system should not be halted and wrote to the official within the Department of Health with responsibility for implementing the new system who subsequently invited representatives from the group to join the Board.

JANUARY 2009

By January 2009, the Minister for Health had stated that the NIHS standard on which the PIPS/GSBF Rights Group indicator was based on, that those suffering serious mental illness or with recent history of self harm problems receiving follow up appointments within a week of discharge from hospital as a 'Priority for Action'², which highlighted the Department's commitment to tackling the issue.

From Pillar to Post: Linking Meaningful Participation to Improved Service Delivery

MAY 2009

In May 2009, the group held an event 'From Pillar to Post: Linking Meaningful Participation to Improved Service Delivery' in the Long Gallery at Stormont, to extract learning from the long and sometime frustrating journey they had been on while trying to ensure that one small change backed by statistical evidence, government, international experts, and service users became a reality. The event, included a key note address by Dr. Helen Potts, the Chief programs Officer of Health Programs with Physicians for Human Rights in Boston who is an expert in participation in health systems internationally. Helen validated the work of the group and articulated the links between meaningful participation and improved service delivery.

The group used both the content and the setting of the event at Stormont Parliament Buildings, to brief and lobby MLAs on the issues and apply pressure on the Department to adhere to its commitment to implement the CBYL system which had now failed to be implemented by the original deadline of April 2009. As a result of this, the Health Committee which was briefed by the Department that evening pushed for renewed vigour in the implementation of the CBYL and a new deadline for 10th October 2009, was set. Since then, the deadline was moved again to the 30th October, *again* to the 30th November, and *again* to 2nd December. It has now been set for the 13 January 2010.

What's next?

The group are currently engaging in interviews with other service users who have experience of participating on consultative structures with mental health service providers. It is envisaged that this will raise awareness on how useful

² Priority for Action for 2009–2010 (one of 12–15 annual priorities for his department that are monitored by the Minister and his office)

participation can be to achieve change. Through the systematic use of indicators to identify and monitor change, service users will be able to identify whether government bodies are progressively realising their obligations to provide the highest attainable standard of mental health.

“The human rights based approach to health indicators is not only a tool to help states, and others, measure and monitor the progressive realisation of the right to health. Additionally, the approach includes features, such as disaggregation, participation, and accountability that, if integrated into health policies and programmes, are likely to enhance their effectiveness.”

Professor Paul Hunt (former UN Special Rapporteur on the right to the highest attainable standard of health) and Gillian MacNaughton

The CBYL experience has shown that it is vital that mechanisms exist that allow for other service users to identify small but vital changes in how services are delivered, and ensure the changes are made promptly and effectively. The PIPS/GSBF Rights Groups campaign for service user participation in a decision that affect them, has led to the ongoing implementation of a new appointment system that will save lives.

The challenge now is to ensure that lessons are learned to ensure that this example can be replicated.