**Response from the Participation and the Practice of Rights organisation to the call for contributions from the UN Special Rapporteur on extreme poverty and human rights, Magdalena Sepúlveda, on the human rights approach to participation of persons living in poverty in decisions that affect their lives**

Participation and the Practice of Rights organisation provide tools and support to marginalised groups actively asserting their right to participate in economic and social decisions which affect their lives. Located in Belfast, Northern Ireland, we currently work with a range of people in poverty including groups of social housing residents; mental health service users, carers and bereaved families; the long term unemployed; social welfare recipients; survivors of domestic violence and people experiencing homelessness.

We would like to submit information in relation to the distinctive experiences of the use of PPR’s human rights based approach to participation of two of these groups.

 **1. The Seven Towers Residents Group**

**Who is involved?**

The Seven Towers Residents Group is made up of former and current residents of the Seven Towers, a high rise complex of flats in New Lodge, a predominantly Catholic area of north Belfast in Northern Ireland. Since 2007 they have been supported by human rights organisation Participation and the Practice of Rights in using their unique human rights based approach to engage with statutory social housing delivery body – the Northern Ireland Housing Executive and the government department with responsibility for housing – the Department for Social Development, in order to realise their right to adequate housing on the ground.

 Following a series of successful campaigns, over the past 18 months the group has broadened their organising efforts to include residents in poor housing conditions in other parts of north Belfast. All group members are marginalised social housing residents from Catholic communities who are experiencing poverty and social exclusion. Evidence shows that in North Belfast approximately 76% of those on the social housing waiting list in housing stress are Catholic[[1]](#footnote-1), despite the general demographic of North Belfast being only 44.9% Catholic[[2]](#footnote-2). This entrenched religious inequality in housing is long-standing and has not been adequately addressed by government either pre- or post-conflict, despite a £133 million North Belfast Housing Strategy which officially ran from 2000-2007. The Human Rights Based Approach used by the Seven Towers Residents Group places ultimate responsibility for fulfilment and protection of rights on the Northern Ireland Minister for Social Development and works to hold that office-holder to account for the realisation of their right to adequate housing, and to ensure their right to participate in government decisions made that impact their housing.

**How is the participatory process structured and managed and what are its desired outcomes: how is the information about the participatory process distributed to the public including persons living in poverty, what are the procedures employed to allow the public to submit comments, information, analysis or opinions that it considers relevant to the process;**

The participatory process used by the residents includes a mechanism for engaging with duty bearers called the Seven Towers Monitoring Group (STMG). This structure was designed by the Seven Towers Residents themselves, a group directly affected by the housing issues they campaign on.

The STMG is convened by the Seven Towers Residents Group with the support of PPR on at least a biannual basis following the monitoring results of the residents’ human rights indicators[[3]](#footnote-3). These human rights indicators are developed by the residents themselves as an integral part of PPR’s Human Rights Based Approach, in order to monitor if global commitments on the right to housing made by the UK government, are actually being progressively realised on the ground in their community.

Following the residents securing a commitment from the relevant government Minister, duty bearers including the service delivery body, the Northern Ireland Housing Executive, and the Department for Social Development attend STMG meetings and report on how they have taken action to progress the residents’ right to housing in accordance with the human rights indicators. They are also asked to account for their progress or lack thereof towards meeting the benchmarks or targets set by the group which they have decided represent realistic and acceptable evidence of progressive realisation on the ground.

The indicators and benchmarks discussed by the STMG have been compiled through extensive participatory action research amongst the affected group. Specific monitoring results are compiled through a peer survey process which collects quantitative data on various rights issues identified by the group. Qualitative data in the form of residents’ testimony is also collected, as well as photographs of the conditions is also shown. Affected residents are invited to attend the STMG meeting.

**What measures are taken to ensure that persons living in poverty can participate: how are the participants identified, are participants prepared and supported before the consultation(s), are the potential financial and opportunity costs to the participants taken into account what measures are taken to ensure the diversity of the participants in terms of gender, ethnicity, age, etc, how is the participation of marginalized groups living in poverty ensured and supported, for examples indigenous peoples, persons with disabilities, or older persons;**

In order to ensure that all persons living in poor conditions in the Seven Towers can participate in the monitoring, residents knock on the doors of every one of the 384 flats in the Seven Towers complex to do a survey with the residents inside[[4]](#footnote-4). This ensures that everyone who lives there has the opportunity to have their experience of living in the Seven Towers captured. Naturally there are different levels of participation among residents - some will simply assist in completing surveys, while others will participate in other forms of monitoring (for example taking photographs of poor conditions). Many residents participate by reporting problems to the authorities and record responses, and a smaller group of residents will join the core group who drive the process.

Generally those residents who attend the STMG are those who have undertaken PPR’s Development Programme[[5]](#footnote-5), which is on offer to all residents. Increasingly however, as knowledge about the work of the Seven Towers Residents Group has spread, residents outside this framework wish to participate to express their individual experience of living in the Seven Towers. One example of this was a resident who was impacted by a fire on another floor which damaged his flat who attended the STMG specifically to ask questions around the failure to adequately address the damage. A pre-meeting is held to develop group strategy and ensure group members of the support available from PPR during and following the meeting.

The role of the PPR Development Worker is central to the affected group’s active and meaningful participation in the STMG. Through the PPR Development Programme, the Development worker is key to building group members skills and encouraging the more experienced activists to act as mentors, leading by example and sharing their experience with newer participants. The agenda of the STMG meeting is decided by the residents in advance and is sent out to the Northern Ireland Housing Executive and Department for Social Development in advance. The meeting is chaired by a member of the Seven Towers Residents Group with the support of PPR where necessary and is held in the offices of PPR where the residents are more comfortable, rather than the government offices. Any costs incurred by residents as a result of their participation are met by PPR, e.g. transport, childcare and providing refreshments and lunch. As far as possible the residents attending the STMG meeting are reflective of the demographic of those who live in the Seven Towers flats in terms of age range, male/female (although mostly female), those with disability those without, those with children, those without.

Information about demographic is collected in the surveys and linked to outcomes e.g. in March 2011, 39% of the flats where the occupants include children contain damp and/or mould growth. Medical studies have shown that dampness and or mould growth in homes has a particularly acute affect on the health of children – a conclusion identified in the survey with only 2 of those homes with children and damp/mould not reporting respiratory problems fro children.

Detailed minutes of the meeting are recorded by PPR with a view not only to record decisions and outcomes of the STMG, for the purposes of accountability, but also to capture any barriers to participation.

**What are the particular challenges faced, or obstacles that have to be overcome,
to ensure meaningful participation by those living in poverty;**

PPR’s work with the Seven Towers Residents Group has identified that the meaningful participation of the affected group requires a great deal of support which must be independent of the state authorities. The particular challenges and obstacles in this regard are numerous, some of the most common, however, include the following.

The personal circumstances of the affected group mean that often participants live in a ‘narrow space’, dealing with unpopular issues and a notable lack of resources and allies. The PPR Development Programme is designed to build the appropriate skills to build a solid case and organise around these factors.

Often a first step to potential participant involvement is dealing with the natural and appropriate dissatisfaction and disillusionment of residents with previous government led consultative mechanisms or community development based initiatives which have yielded little change. Clear differences between the PPR approach and existing approaches need to be established with people. In the particular example of the Seven Towers Residents Group, the local housing authority already had in place a series of consultative structures which served only to legitimise decisions made by the dutybearer. Eventual attempts made to subsume the STMG structure into these existing bodies were resisted by the group.

The issues of power and accountability directly impact participation and often act as barriers to meaningful participation. In December 2011, for example, the government representative threatened to withdraw from the STMG structure over a dispute about the detailed nature of the minutes of the meeting. Furthermore, the duty bearers response to the problems identified by the affected group has often impeded progress towards resolution. Numerous attempts to redefine the problem, for example, for years the local housing authority objected to the labelling of ‘dampness’, which once found the housing authority must act to remove, instead preferring to use the term ‘condensation. A previous government Minister with responsibility for housing, acknowledged this and stated in a radio interview in 2009 that she felt there was ‘a healthy conflict’ between the two definitions but that the Housing Executive had decided the problem was condensation. Only in December 2011, following years of evidence presented by the Seven Towers residents, evidence from experts in Health and Housing Prof. Geoff Green and David Ormandy, and the presentation of visual evidence by residents during the STMG meeting, did the local housing authority accept that there was a problem with dampness in the Seven Towers.

Engagement with the duty bearers through the STMG structure is also often punctuated by dutybearer dissatisfaction of and criticism of the indicator/benchmark process. There is little appreciation by the dutybearer of the importance of the affected group setting the indicators and benchmarks independently of government, and a reluctance to be monitored externally. It is of significant value to the residents that in response to this, they can rely on the fact that international human rights experts have validated the Human Rights Based Approach including the indicator and benchmark selection process that they use at various International Hearings held by PPR and the residents in the last five years. This was further supported with the inclusion of this approach as a model of best practice by the OHCHR in the latest publication on indicators.[[6]](#footnote-6)

**How successful is the process in terms of the levels of participation of persons
living in poverty;**

On its own, PPR’s experience is that simply making existing decision making processes ‘more inclusive’ is not enough. Repeatedly residents of the Seven Towers, despite having established the STMG, have discovered that decisions are not made ‘in the room’ with the duty bearer. The Seven Towers Residents Group has had to use political lobbying from above, international expert pressure and media lobbying and protest to affect decision making and apply pressure. What the STMG has done, however is force the relevant duty bearers into a human rights based approach form of accountability where there can be direct scrutiny of their activity by rights holders.

Indeed, this participation has yielded some positive responses from the duty bearer. For example, the local housing authority, the Northern Ireland Housing Executive, have made reference in the past to the impact of indicator/benchmark monitoring and reporting system through the STMG structure as having the effect of ‘focusing’ or ‘targeting of resources’ of the Housing Executive management and staff towards the delivery of improvements especially in terms of financial options.[[7]](#footnote-7)

PPR are also keen to record the empowering nature of participation in this structure for residents themselves, in that there is a transformative benefit of people acting as the agents of their own change. There are noticeable and considerable increases in resident self confidence and skills development, which in turn helps them to support less experienced residents. PPR are currently devising a recognised accreditation programme through which residents skill development from participation can be recorded and used by them in other areas of their life such as access to further education or employment.

PPR has previously mapped differing levels of resident participation in monitoring and campaigning to chart the progress of our approach in supporting vulnerable and marginalised groups to take steps outside of their comfort zone and participate. In the last annual indicator monitoring cycle for example, 224 resident surveys were collected. 115 residents signed a petition asking for the Minister to ensure that the proposed cladding plans were capable of addressing resident’s needs. At least 24 residents took part in active campaigning work including taking part in DVDs, engaging with the media, peacefully protesting and writing letters. The process was driven by a core group of six.

**What is the impact (actual or envisaged) of the participatory processes on the
design or implementation of the activity/legislation/policy/programme: what follow-up
is undertaken after the process with the participants, if any how are the results
documented and how are they used;**

**Working through the STMG structure the group have achieved significant improvements in the flats complex including the complete removal of pigeon waste from communal landings, the replacement of the sewage system which frequently overflowed through baths and sinks, and the rehousing of the majority of families into suitable accommodation. The residents were also able to force improvements in a proposed multi million pound scheme to cover the outside of the buildings in a PvC rainscreen which would not progress their rights**[[8]](#footnote-8)**. The proposal will now include insulation.**

Although certain positive outcomes and improvements have been achieved, the general power imbalance between duty bearer and citizen as well as the decision making structure itself, still exists and needs to be constantly addressed. Seven Towers residents are currently doing this by broadening the geographnical area in which residents are organised to campaign and through continuing to build strong alliances with experts and other organisations and groups. **What are the lessons learnt from the process;**

The state prefers to deal with the participation of the affected group through its own ‘consultation structures’, which are often not designed to foster meaningful participation.. The Seven Towers residents’ experience of the existing structures for social housing residents to participate in decision making was that it was tokenistic and incapable of dealing with the most basic breaches of their human rights – for example resolving chronic sewage ingress into households for over a decade. The process is designed and controlled by the duty bearer, and the outcomes from this process reflect the duty bearers priorities as opposed to those experiencing human rights abuses. By designing their own process and using pressure to force the duty bearer to participate, the residents were able to control the agenda but the local housing authority and government representatives constantly tried to resist this.

It is from this that the importance of developing allies and applying pressure can be observed. The Seven Towers residents have held three international hearings where their work has been commended and validated by experts and received support from experts including former Commissioner for Human Rights at the Council of Europe Mr Thomas Hammarberg, UN Special Rapporteur on the Right to Adequate Standard of Living, Ms Raquel Rolnik and former UN High Commissioner for Human Rights and former President of Ireland, Mrs Mary Robinson who has referred to their work as “groundbreaking”. Furthermore, during the UN Committee on Economic Social and Cultural Rights most recent monitoring of the United Kingdom including Northern Ireland, residents successfully lobbied the Committee to include reference to continuing untackled religious inequality in social housing in North Belfast.[[9]](#footnote-9)

Locally, the use of the press to expose the poor and ineffective responses taken by duty bearers to identified issues has also been effective in achieving redress. It is clear that for the process to be effective, residents must also exert pressure from outside it.

Any meaningful change identified by the residents as necessary which has been achieved, e.g. the removal of pigeon waste, has been as a result of this pressure. In contrast to this, change which is identified by the state as necessary, such as the proposals for the PvC rainscreen, is a change which is prescribed at the duty bearers pace and on their terms. The response is often an attempt by the duty bearer to alleviate public pressure created by the group by addressing the symptoms of the problem, and not the structural nature and cause of the issue itself.

Government’s participation in a human rights compliant decision making framework is reluctant. We have seen attempts to ‘quiet’ the residents campaign by rehousing activists, questioning the mandate of certain residents to participate, and also through the use of punitive measures against activists, for example unfair charges have been imposed on activists which are removed when disputed and attempts have been made to arbitrarily evict residents which have been withdrawn when challenged.

 **What additional changes would have been necessary to ease the constraints on the
participation on persons living in poverty;**

Numerous changes are necessary in order to remove the constraints imposed on participation of persons living in poverty. One practical example, involves improved access to information held by the duty bearer. The importance of having access to information was underlined for the Seven Towers residents when they uncovered in a series of emails released under Freedom of Information legislation that an independent building contractor had advised the local housing authority of safety concerns regarding the balconies of the flats. This concern was never communicated to the residents and remedial action was only taken by the housing authority once the residents exposed the information and demanded action in the national press.

It is very clear that access to information from duty bearers is a key issue in monitoring the protection and promotion of rights by rights holders and thus the ability to participate in matters affecting this. Stronger accountability mechanisms for redressing problems with information accessibility would be useful. The Seven Towers Residents have made use of both national Freedom of Information legislation to gain access to official documents and Data Protection legislation to access their personal housing files from the local housing authority and have encountered problems with both.

The official tender documentation and plans for a multi million pound proposal to install a PvC rainscreen on the outside of the flats took in excess of one year and three separate Freedom of Information Requests to obtain. None of these requests were answered within the statutory timeframe, the two requests which denied access involved the inconsistent use of statutory provisions for exemption and one request involved the use of the appeals process which also resulted in access being denied.

For residents to gain access to their personal housing files, requests were made under Data Protection legislation. The files were granted but only on condition of a fixed monetary charge being provided to the local housing authority. This cost was met by PPR as residents may otherwise have been dissuaded from pursuing the process because of the financial burden incurred.

**Further materials which may also be relevant to this study include:**

“Papering Over The Cracks”; A short film produced by Seven Towers Residents about their campaign accessible here ; <http://vimeo.com/30431946>

Seven Towers Monitoring Group Case Study as referenced in *“Participation and the Rights to The Highest Attainable Standard of Health”* Dr Helen Potts University of Essex Human Rights Centre p.34-35 accessible here: <http://www.essex.ac.uk/hrc/research/projects/rth/docs/Participation.pdf>

The People’s Inquiry: A Right to Housing. Recommendations of the International Panel, particularly Chapter 3 entitled *“Participation as a Process”* available here: <http://www.pprproject.org/sites/default/files/Recomendations%20from%20Int%20Panel%20April%202011%20Ccmpressed%20file.pdf>

**2. The Belfast Mental Health Rights Group**

**Who is involved?**

The Belfast Mental Health Rights Group (BMHRG) is a group of mental health service users, carers and families bereaved by suicide from Belfast, Northern Ireland formed in 2006.

Government statistics show that suicide rates here reached a record high last year in Northern Ireland, with 313 deaths recorded[[10]](#footnote-10). Consistent levels of disproportionately high suicide rates have been recorded in areas such as North and West Belfast, where the BMHRG are predominantly drawn from and which also face high rates of socio-economic deprivation and social exclusion. In a longitudinal study across 426 constituencies in the United Kingdom, Brock et al. found significant differences in the suicide rates between 1991-1997 and 1998-2004 in Northern Ireland. North Belfast’s suicide rate rose from 319th to 11th highest in the UK and in West Belfast the rate rose from 259th to 13th highest.[[11]](#footnote-11)

The Belfast Mental Health Rights Group use PPR’s Human Rights Based Approach to engage with statutory agencies involved in mental health service delivery such as the Belfast Health and Social Care Trust and the Health and Social Care Board. The approach places ultimate responsibility for the fulfilment and protection of the right to the highest standard of mental health with the Northern Ireland Minister for Health, Social Services and Public Safety.

  **How is the participatory process structured and managed and what are its desired
outcomes: how is the information about the participatory process distributed to
the public including persons living in poverty, what are the procedures employed
to allow the public to submit comments, information, analysis or opinions that it
considers relevant to the process;**

The Belfast Mental Health Rights Group campaigned for a new appointment system for mental health patients visiting Accident and Emergency Departments of hospitals for treatment. The system, the ‘Card Before You Leave’ (CBYL) was based on evidence that the period following discharge was particularly high risk for suicide and followed similar models from other jurisdictions e.g. the Green Card Scheme in Australia. Following a three-year campaign, the Belfast Mental Health Rights Group secured the commitment of the Minister for Health to put the Card Before You Leave system in place, requiring that those attending Accident and Emergency Departments for mental health care were provided with the date and time of their next appointment before they left the premises. The key participatory process to be described here is the Card Before You Leave Implementation Board, convened by the Minister to ensure the implementation of the new system.

The Card Before You Leave Implementation Board is chaired by the Northern Ireland Health and Social Care Board, who are charged with commissioning and developing health and social care services in Northern Ireland. The Chairperson is a high-ranking civil servant in the Performance Management and Service Improvement Directorate of the HSC Board. The HSC Board convene the meetings of the CBYL Implementation Board on a semi regular basis. Between April 2010 and May 2011, for example, seven meetings were arranged, with five going ahead and two being postponed. The purpose of the Board, according to the Terms of Reference, is to “oversee and support the implementation of the Card Before You Leave scheme”.

The Board members from different Health Trust areas report on how Card Before You Leave is being implemented in their area, common concerns are discussed with Board decisions being made about how to overcome any obstacles which arise.

Information about issues discussed at CBYL Board meetings including minutes and agendas are generally unpublished by the HSC Board, although they are normally circulated to Board members. Occasionally, the HSC Board will give updates as to the progress of CBYL to the public through service user consultative structures which it convenes, although this is on an ad hoc basis. When CBYL was launched in 2010, media and the general public were invited to attend, but since then information about the CBYL and its implementation has generally only been made public by the Belfast Mental Health Rights Group through newsletters and events which are aimed at people experiencing similar issues as them.
 **What measures are taken to ensure that persons living in poverty can participate:
how are the participants identified, are participants prepared and supported before
the consultation(s), are the potential financial and opportunity costs to the participants taken into account what measures are taken to ensure the diversity of the participants in terms of gender, ethnicity, age, etc, how is the participation of marginalized groups living in poverty ensured and supported, for examples indigenous peoples, persons with disabilities, or older persons;**

Measures taken to ensure persons can participate in the CBYL Implementation Board have been designed and implemented by the affected group and not the state. When the CBYL Board was originally convened, the BMHRG despite having designed and campaigned for the initiative were not invited to sit on the Board. Instead a service user who had previously been involved in other state sponsored consultative structures was asked to represent service users on the Board. This service user was unsupported and not briefed as to the nature of the business neither of the Board nor to the group’s involvement. The BMHRG viewed this invitation to participate as tokenistic and when the service user became aware that the BMHRG had not been invited to participate, she stepped down as a representative on the Board and asked that the BMHRG be involved in her place. BMHRG currently have two seats on the Board and are heavily outnumbered by HSC and Trust officials.

In recognition of the power dynamic and the BMHRG’s experience on other consultative structures, the Belfast Mental Health Rights Group identified a series of actions that would be required from the duty-bearer; the Health and Social Care Board, in order for their participation to be active and meaningful in accordance with international human rights standards. Each of these actions was based in international human rights law and was shaped into ‘participation indicators’ to monitor the duty-bearer’s performance in according the group meaningful participation.

|  |  |
| --- | --- |
|  | **INDICATOR** |
| **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 properly 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 |
| Our expenses were covered |

The Participation indicators were as follows:

BMHRG lobbied for the inclusion of the participation indicators in the CBYL Board Terms of Reference to ensure that the importance of their monitoring was central to the business of the Board. The Card before You Leave Board is thus unique in Northern Ireland in its use of international human rights standards to monitor the participation of directly affected persons on the Board.

 However, the Group’s experience was that despite their monitoring, little attention was paid to the indicator results; often with meetings finishing before time was allowed for the Group to present their monitoring results and thus their participation did not improve. In January 2011, almost eighteen months after the group first became involved, it was agreed at the request of the group that a standing item on the agenda of each meeting would be included to specifically address this and allow for meaningful discussion of issues arising from BMHRG’s participation indicator monitoring.[[12]](#footnote-12)

As a group directly impacted by mental health issues, part of their Belfast Mental Health Rights Group’s work is to monitor the human rights indicators they have set to gauge change on the ground.[[13]](#footnote-13) They do this by surveying others with experience of visiting Accident and Emergency Departments for mental health treatment at six month intervals. This ensures that the experience of mental health service users outside the group is captured and informs their participation on the CBYL Board. By continuing to monitor their own human rights indicators the BMHRG can assess if changes made at policy level were having an impact on the ground in their communities.

Of those service users and carers who participated in the BMHRG’s last round of monitoring in the spring of 2012, the following demographics can be observed.

|  |  |  |
| --- | --- | --- |
|  | **Gender** | **Age** |
|  | **Male** | **Female** | **16-26** | **27-39** | **40-49** | **50-60** | **61-70** |
| **Service User Survey Participants** | 60% | 40% | 10% | 40% | 30% | 10% | 10% |
| **Carer Survey Participants** | 25% | 75% | 12.5% | 37.5% | 31.3% | 18.0% | - |
| **Combined Service User/ Carer Survey Participants** | 38.5% | 61.5% | 11.5% | 38.5% | 31% | 15.4% | 3.8% |

 **What are the particular challenges faced, or obstacles that have to be overcome,
to ensure meaningful participation by those living in poverty;**

The experience by the Belfast Mental Health Rights Group of participating in the Card Before You Leave Board has identified particular challenges for those living in poverty who seek to participate in decisions made about their lives. Firstly, the issue of power; every aspect of the meeting is controlled by the Health and Social Care Board, from the agenda to the minutes of the meeting and the recorded actions. Agreements made to work to meet the participation indicators set by the BMHRG such as for example, that minutes and relevant papers should be sent two weeks in advance were not adhered to.[[14]](#footnote-14) This failure has also demonstrated the importance of accountability and transparency in terms of information provision. Key documents were not sent in advance of the meeting so BMHRG could have adequate time to prepare and fully scrutinise decisions which were being made by the Board.

Failure to provide accessible information in a timely manner also contributed to a growing absorption of BMHRG’s time and energy into attempting to ascertain the details of decisions which were frequently being made ‘away from the table’. In late 2010, for example, BMHRG were forced to withdraw from meetings of the Card Before You Leave Board until the Board made clear how the definition of the Card Before You Leave scheme was changed from providing a fixed next day appointment to a follow up phone call.

Government has also consistently attempted to redefine the problem identified by the affected group as in need of change. Despite the articulation of the group of problems in mental health service delivery at an Accident and Emergency (A&E) setting, and evidence identifying that deprived communities disproportionately access health care through A&E, the government has repeatedly stated that people in mental health crisis should not go to A&E.

Moreover, concerns highlighted by Health and Social Care Board in the delivery of the Card Before You Leave system surrounded the resource implications of people who did not attend the fixed next day appointment. BMHRG relied on support from PPR in analysing complex raw data for Did Not Attend rates and only with this support was it possible to identify that the data used by the Health and Social Care Board to support their concerns was not ‘clean’ in fact it contained secondary irrelevant data which did not have the same resource implications and acted to artificially inflate the Did Not Attend rate. Since this support was not provided by the state, it would have been difficult for BMHRG to fully analyse the extent of the problems with the evidence base used.

**How successful is the process in terms of the levels of participation of persons
living in poverty;**

On their own, participatory processes are not enough to change outcomes. Experience has shown that decisions are not made ‘in the room’. In order to ensure improvements in the States promotion and protection of the Belfast Mental Health Rights group’s right to participate in decisions affecting them, and to ensure that such participation is meaningful, group members have consistently had to apply external pressure for progress.

 BMHRG have had to use political lobbying, international expert pressure and media exposure as well as peaceful protest to affect decision making. For example, when it became clear that decisions were being made ‘away from the table’ about the definition of CBYL and the service it would provide to the most vulnerable, the group were forced to withdraw from the Board, write to the Minister, the Northern Ireland Assembly scrutiny committee, protest outside the HSC offices and use the media before any answers about CBYL would be given. The combined result of these actions forced the relevant duty bearers into a human rights based approach form of engagement with affected groups which would otherwise never have happened.

Following prolonged campaigning by the BMHRG to expose the failures of the Health and Social Care Board to honour their responsibility for progressing the participation indicators, a meeting was set up between senior management at the Health and Social Care Board and the BMHRG. In this meeting, senior management commented on “how useful” it was to have the barriers to the group’s participation so clearly identified. The indicator format, led the Health and Social Care Board Management to provide extra administrative support to ensure that the indicators would be met and that participation could be improved. For the first time since the Boards inception, in April 2011, the minutes, agenda and relevant papers were received by the BMHRG two weeks in advance of the meeting.

 **What is the impact (actual or envisaged) of the participatory processes on the
design or implementation of the activity/legislation/policy/programme: what follow-up
is undertaken after the process with the participants, if any how are the results
documented and how are they used;**

Through the BMHRG’s participation on the Card Before You Leave Board, the following impacts on the appointment card system can be identified.

The Group have ensured that the system provides a fixed next day appointment for those discharged from an A&E setting who are in mental health distress. The system was previously initially implemented in some areas of Northern Ireland as a follow up phonecall to offer a fixed appointment. BMHRG were clear that this was not true to the original design of the policy, it was not supported by international best practice and in their experience it would not provide an adequate safeguard to vulnerable people. By January 2011, one year after the scheme was launched, the Card Before You Leave was operating as a fixed appointment system everywhere in Northern Ireland. BMHRG continue to monitor this in surveys to ensure this change is sustained.

BMHRG have also influenced the arrangements for the monitoring and evaluation of the scheme by ensuring for example that ‘clean’ data is used to record the numbers of those who ‘Did Not Attend’ the next day appointment.

**What are the lessons learnt from the process?**

BMHRG Participation Progress Report charts many of the lessons learned by the group in their work.[[15]](#footnote-15) Additionally, it is clear that meaningful participation requires support. This is rarely provided by the state whose understanding of ‘participation’ is often tokenistic and does not correlate with international human rights standards. Substantial and sustained development work with the affected group, provided by PPR, is necessary to ensure not only access to a forum for participation but also access to forums whereby accountability for failures to promote participation could be achieved. For example, support is necessary not only for meaningful participation at the Card Before You Leave Board but also when seeking redress for failures at the Board. The Belfast Mental Health Rights Group has successfully engaged with the Northern Ireland Assembly Health Committee, local politicians, the media and has built alliances with other affected groups. For participation to be meaningful, accountability must be effective and accessible.

Furthermore, it is important to recognise that participation is difficult. Real participation must be differentiated from the ‘participation’ prescribed by states which is non specific and which doesn’t address the power imbalance.

 **What additional changes would have been necessary to ease the constraints on the
participation on persons living in poverty; and**

Of significant importance, which has been covered in depth throughout this submission, is the requirement that information should be accessible, both in terms of format and the timeliness. BMHRG, in a separate human rights indicator, monitored information supplied by government through official Freedom of Information requests against international human rights standards on transparency and accountability and recorded very poor results. More information on the standards, monitoring and results can be found in the BMHRG’s latest Progress Report entitled “Services at Breaking Point: Fighting to Have Our Voices Heard”.[[16]](#footnote-16)

The relationship of the Card Before You Leave board is one which does not just involve the affected group and the state i.e. the Belfast Mental Health Rights Group and the Health and Social Care Board. The Board also contains representatives from health service delivery organisations in Northern Ireland responsible for the implementation of the scheme in specific areas. Failure of these organisations to abide by agreements made by the Health and Social Care Board to the Belfast Mental Health Rights Group can derail the process. For example, there is currently an ongoing dispute at the Board which has resulted in no meetings of the Board being called for over three months. It was agreed by the Health and Social Care Board that the Belfast Mental Health Rights Group could use audio recording equipment during the meeting so that they could later reflect on the voluminous information being communicated orally, as detailed minutes to this effect were not kept. Following an objection from a health service delivery organisation within the Board however, this agreement was rescinded without recourse to any conflict resolution mechanism or appeal process. It is necessary to ensure that respect for rights implementation is maintained by all participants and that the state recognise their obligation towards ensuring that other actors do not impede progress.

Belfast Mental Health Rights Group’s experience in the last 4 years provides evidentiary support for the need for, what Professor Helen Potts, formerly of Physicians for Human Rights has referred to as an *“independent participation facilitator”[[17]](#footnote-17)* who can adjudicate through institutional mechanisms designed for participation, an adherence to human rights standards and a recourse for action when these standards are not met.

 **Further materials which may also be relevant to this study include:**

* What We Know About Change DVD available to view at http://www.youtube.com/watch?v=Zkek7X0LmRc&list=UU3iMuDl6lGTB\_K6JzTgsOpw&index=5
* BMHRG’s latest Progress Report entitled “Services at Breaking Point: Fighting to Have Our Voices Heard” available at <http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf>

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1. The Northern Ireland Housing Executive Social Housing Waiting List officially records 46% of those in housing stress as Catholic using a recently changed process whereby the applicant ‘self reports’ their religious background. However, this process has left a significant number of those in housing stress with an unaccounted for religious background. Under the previous system of measurement, the numbers of Catholics in housing Stress would amount to 76% of the total and this figure is widely used unchallenged. [↑](#footnote-ref-1)
2. Northern Ireland Census 2001 records the North Belfast Parliamentary Constituency population as 44.9% Catholic and 51.9% Protestant. [↑](#footnote-ref-2)
3. See example of Seven Towers Residents Group Indicators and monitoring in the Seven Towers Residents Forth Progress Report available at <http://www.pprproject.org/sites/default/files/documents/st_fourth_progress_report.pdf> [↑](#footnote-ref-3)
4. See sample survey document entitled “Final Second Survey Seven Towers” [↑](#footnote-ref-4)
5. See additional note for more on the PPR Development Programme entitled “The PPR Development Programme and Human Rights Based Approach” [↑](#footnote-ref-5)
6. See Human Rights Indicators: A Guide to Measurement and Implementationhttp://www.ohchr.org/Documents/Publications/Human\_rights\_indicators\_en.pdf [↑](#footnote-ref-6)
7. Comments made by Northern Ireland Housing Executive Area Manager, Mr Sean McKenna at the 2nd Housing Hearing, 23rd January 2009. [↑](#footnote-ref-7)
8. See for example “A Human Rights Budget Analysis of the Northern Ireland Housing Executive’s current plans to clad the Seven Towers Flats” (June 2011) available at <http://www.pprproject.org/sites/default/files/BUDGET%20ANALYSIS%20JUNE%202011.pdf> [↑](#footnote-ref-8)
9. ##  Concluding Observations of the Committee on Economic, Social and Cultural Rights United Kingdom of Great Britain and Northern Ireland, the Crown Dependencies and the Overseas Dependent Territories (May 2009) E/C.12/GBR/CO/5

 [↑](#footnote-ref-9)
10. NINIS Deaths by Cause dataset 2011 [↑](#footnote-ref-10)
11. A. Brock, A. Baker, C. Griffiths, G. Jackson, G. Fegan, and D. Marshall, “Suicide trends and geographical variations in the UK, 1991–2004,” *Health Statistics Quarterly* 31 (2006), p. 15. Available

at <http://www.statistics.gov.uk/articles/hsq/HSQ31suicide_trends.pdf> [↑](#footnote-ref-11)
12. For further information on the BMHRG’s participation indicators and most recent monitoring at the Card Before You Leave Board, please see the BMHRG’s latest Progress Report entitled “Services at Breaking Point: Fighting to Have Our Voices Heard” available at <http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf> [↑](#footnote-ref-12)
13. The full list of mental health human rights indicators are included in the BMHRG’s latest Progress Report entitled “Services at Breaking Point: Fighting to Have Our Voices Heard” available at <http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf> [↑](#footnote-ref-13)
14. For a full breakdown of instances where this participation indicator was not met please see the table on page 25 of the BMHRG’s latest Progress Report entitled “Services at Breaking Point: Fighting to Have Our Voices Heard” available at <http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf> [↑](#footnote-ref-14)
15. Please see especially page 29 of the BMHRG’s latest Progress Report entitled “Services at Breaking Point: Fighting to Have Our Voices Heard” available at <http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf> [↑](#footnote-ref-15)
16. Specifically, please see pages 20-22 of the BMHRG’s latest Progress Report entitled “Services at Breaking Point: Fighting to Have Our Voices Heard” available at <http://www.pprproject.org/sites/default/files/Final%20Participation%20Progress%20Report%20May%202012%20compressed.pdf> [↑](#footnote-ref-16)
17. Dr Helen Potts, speaking at PPR event entitled “From Pillar to Post: Linking Meaningful Participation to Improved Service Delivery,” in Belfast, Northern Ireland in May 2009. [↑](#footnote-ref-17)