
Services At Breaking Point: Fighting To Have Our Voices Heard

Participation Progress Report

A review by mental health service users, their carers and families bereaved through suicide into what progress the mental health service is making to ensure that participation is meaningful



May 2012

Belfast Mental Health Rights Group Report

“We’re the people on the ground; we’re the people with the voice. Especially with mental health, we’re being told how we should feel without giving us the chance to say how we feel and what we need. But we will march on and we will fight because you know we are all human and we need the respect and the dignity we all deserve.”

Bette, Belfast Mental Health Rights Group

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INTRODUCTION

The Belfast Mental Health Rights Group (BMHRG)



The Belfast Mental Health Rights Group (BMHRG) are a group of service users, carers and families bereaved through suicide. We come from all over Belfast, but especially the North and West of the city where suicide rates are particularly high. Together we have worked since 2007 to make a change in mental health services by ensuring that people are meaningfully involved in decision making.

In January 2010, the Minister for Health launched the Card Before You Leave (CBYL) scheme, an appointment card system that we campaigned for. This means that anyone who presents themselves at A&E with self harm or suicidal thoughts, but is deemed low risk and discharged, must receive the details of their follow up appointment before they leave hospital. Whilst even getting this change was a great success, it will be useless unless things on the ground change so we've spent the last year working to collect information about people's experiences at A&E to make sure government are living up to their promises.

The results here show that the situation is not improving as it should. It feels almost like watching a drunk man taking one step forward and then stumbling two steps back. That is not good enough.

We're asking you to join with us in fighting to ensure that our voices are heard. Join with us to fight to ensure that services that are so badly needed don't fall any further back and that things improve. Join with us to make change!

SECTION 1:

Why do we need to change the way we 'do' participation?



THE EVIDENCE ON THE GROUND

Problems accessing services are experienced most acutely by service users themselves, as well as by their carers or family/friends. As Belfast Mental Health Rights Group member Kathy Gilliland commented;

"We are the people on the ground who have suffered under the services provided which are not adequate...you can become very ill yourself and the services are not in place, so there is a good reason to be involved - we are the evidence!"

Despite this, service users and their carers are largely 'left out in the cold' when it comes to decision making around these issues.

Some of the most important issues in terms of accessing mental health services through Accident and Emergency departments (hereafter referred to as A&E) have been monitored over the last year by the Belfast Mental Health Rights Group. In all, they collected the views of 58 people who had either been to A&E in crisis themselves or who had supported someone else through a crisis. The evidence shows that despite these issues being discussed at government level, little change in outcome has occurred. Despite public funding being spent on these issues, things have only gotten worse.

Worryingly, the most common theme arising from the research surveys and interviews we have carried out over the last year into matters connected with experiences at A&E for those in mental health distress and their carers is the issue of respect.

In 2010, a carer who had supported someone in crisis during an attendance at A&E told us that *“the main issue with the mental health system is the lack of dignity, respect and duty of care towards the most vulnerable”*. Many patients themselves also told us that they felt *“in the way”*, with some commenting that on leaving they *“felt worse than when I entered”*.

In 2010, only 17% of those people who had been to A&E in mental health crisis felt that they had been respected.

By 2011, the situation had improved slightly, with 25% of those who spoke to us stating that they felt respected. However, this still leaves the overwhelming majority of those who attended A&E in mental health crisis, 75%, stating that they did not feel respected.

One man who spoke to us told us that during his nine hour wait in the Mater hospital he felt like he was *“in the way”*. He stated that he was treated as less important because he had a mental illness and not a physical injury, he said *“I know it wasn’t my leg broke, but I was still sick.”* Having never sought help for his depression before because, as he explained it *“my upbringing was, if you’re a man, you keep your feelings to yourself”*, he found the entire experience to be *“like knocking doors and nobody answering”*.

Others commented that the treatment was *“abrupt, formal and distant”*. One individual who had supported someone in distress at A&E felt that the treatment showed an inappropriate lack of consideration for the six and half hours they had waited and the distress they had experienced.

A young person who attended A&E also pointed to issues connected with drugs or alcohol and told us that *“no-one understands a young person with mental health problems, they presume you are a drunk or looking for attention.”* Another told us of his experience of seeking help at A&E when in crisis, *“I didn’t know where to turn to, my friend committed suicide four years ago and they told me not to drink and the stress will go away”*.

The problems in A&E are at crisis point.

If things are to get better then there needs to be a change in the way decisions are made about how people in mental health distress are treated when they go to A&E for help. If the outcome is to change, so must the process.

Issue 1

People in mental health crisis don't have enough information about the treatment they are supposed to receive when they are in distress, and nor do their carers



BMHRG: Why this issue is important

Being in mental health crisis or supporting a family or friend in crisis is traumatic enough without the added complication of mixed messages or not knowing what is going to happen. Having a clear plan can help keep people safe.

In 2010, only 20% of people who had been in A&E for help when they were in mental health crisis and their carers together told us that they were happy with the level of information they received about their treatment and the care pathway.

For a lot of people, getting information at A&E is difficult. One survey respondent told us that the only information she was given by the staff was that she would be sent home as soon as her assessment was complete. Another told us that during his twelve hour wait in the City Hospital A&E he tried to find out how long he would have to wait as well as for what he was even waiting for, but he found the staff unhelpful. Many others have stressed that information about treatment and discharge is important, not just for them but also for their carers or family. Reflecting on his discussion with the doctor before being discharged, a survey respondent noted that information was important *"not so much for myself, but for my partner or whoever was with me, for them to know what to do next"*. Additionally, another respondent commented that since the discussion about discharge and support was not attended by anyone else, he was responsible for remembering all the information - which can be an additional burden during a stressful time when you are unwell.

This is despite the fact that both international human rights law and local policy states that being informed about your treatment and having the option to have your carer informed about your treatment is important:

WHAT DOES HUMAN RIGHTS LAW SAY?

“Obligations to fulfill the right to health require the State to undertake actions that create, maintain and restore the health of the population. Such obligations include :... (iv) supporting people in making informed choices about their health”

United Nations Committee on Economic Social and Cultural Rights, General Comment 14, paragraph 37

WHAT DOES LOCAL POLICY SAY?

“There must be a partnership approach where people with a mental health need or a learning disability are not passive recipients of services but active participants, along with their family and carers”

Bamford Action Plan 2009-2011 page 31

Having information about your treatment is so important that by 2011, we said that government should have ensured that 85% of people were satisfied with the level of information they receive in A&E about their treatment and care pathway.

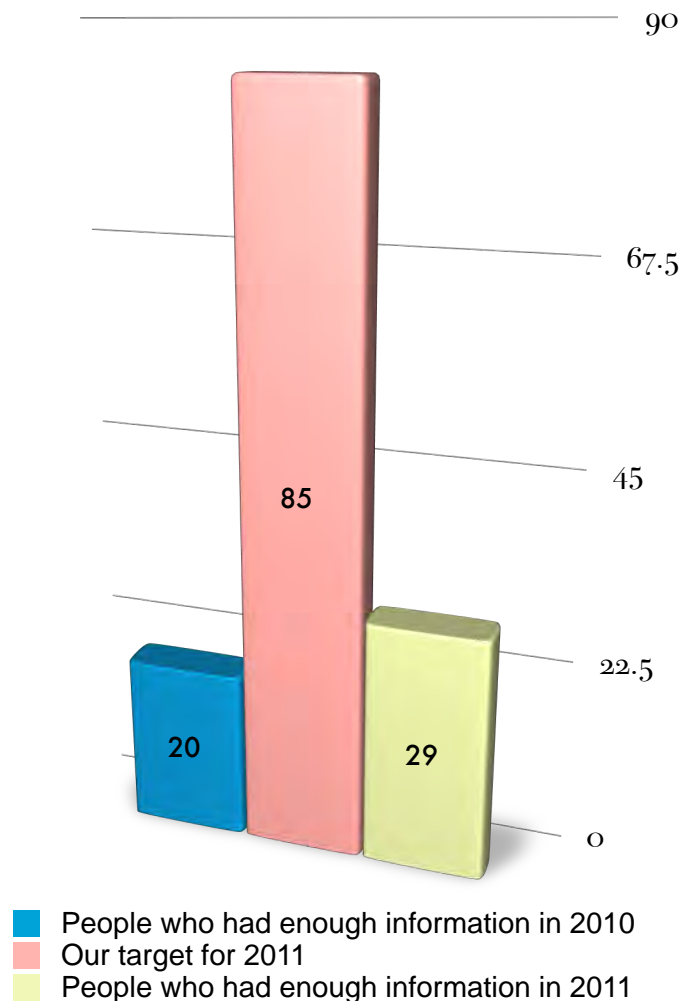
By 2011, things had improved a little, but not enough.

Now 29% of people who had been in A&E for help when they were in mental health crisis and their carers together told us that they were happy with the level of information they received about their treatment and the care pathway.

Our research demonstrates the real need for people using mental health services and their carers to be properly informed about their treatment. Information is the first step to involvement. If the government are serious about ensuring that service users and their carers are not “passive recipients” as the Bamford Review suggested then change must happen. It must be done carefully and with the full involvement of service users however, to ensure that it does not become a ‘tick-box’ exercise. Being informed properly about your treatment means you are better able to contribute information yourself. Giving someone information about their treatment is a basic

sign of respect. Worryingly, this does not seem to be happening now, one service user told us she was “*treated as a timewaster*” and told that her depression and subsequent suicide attempt was “*caused by the menopause*” because the staff were unaware of her fifteen year history of illness with depression.

Another told us that not having the right information about who was treating him and what was going to happen compounded the trauma he was already experiencing. He commented that “*No one ever seems to say, ‘we’re the team who are going to help you now’. It just doesn’t make sense to give ‘em a diagnosis and then leave them in the dark*”.



Issue 2

People in mental health crisis are waiting too long to be treated when they go to A&E



BMHRG: Why this issue is important

“Sometimes when you want to self harm, its so strong that you don’t have the luxury of having time to waste.”

Joanna - Belfast Mental Health Rights Group

In 2010, 45% of people who had been in A&E for help when they were in mental health crisis and their carers together told us that they were waiting over four hours to be treated and admitted or discharged by a doctor.

Long waiting times are increasingly becoming a feature of most people’s experience at A&E. However, the experience of waiting for long periods for those in mental health distress can be especially traumatic since A&E departments are often quite chaotic. This has led to calls for “quiet rooms” by many service user groups in Northern Ireland where people can wait for treatment in a safe environment which is not likely to further worsen their distress. The Belfast Mental Health Group echo this call. Ensuring there is an appropriate space for people to wait will not however, distract from the need to shorten waiting times at A&E - an issue which needs serious attention.

Of the few who told us that they were satisfied with the length of time that they had to wait, one indicated that although she “waited just over an hour” at the time, owing to her illness “it felt like ages, forever, whereas now it seems reasonable” . This gives some insight into how important the issue of waiting times at A&E really is.

Both international human rights law and local policy states that getting the help you need when you need it is important:

WHAT DOES HUMAN RIGHTS LAW SAY?

“The right to health is an inclusive right extending [not only] to timely and appropriate health care...”

Committee on Economic Social and Cultural Rights General Comment 14, paragraph 11

WHAT DOES LOCAL POLICY SAY?

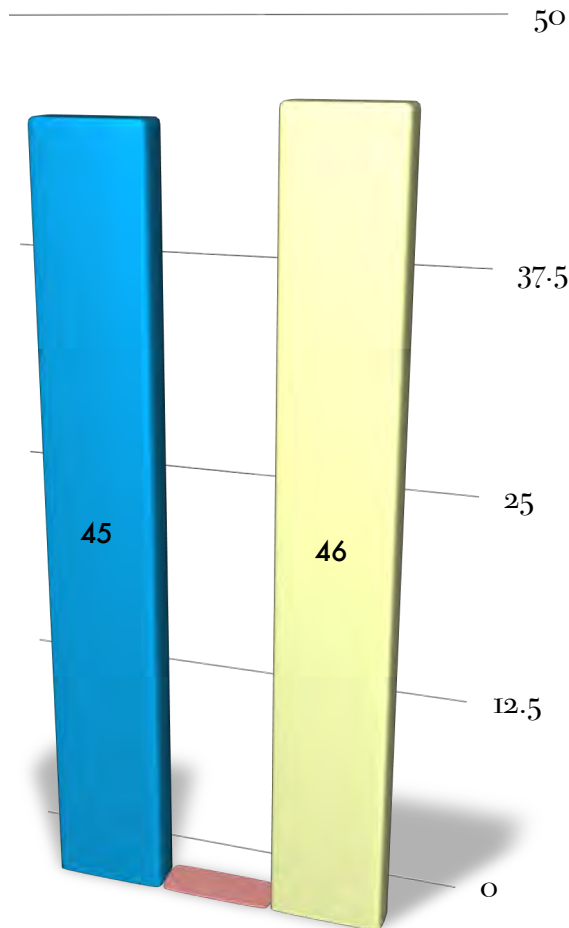
“From April 2010, HSC Board and Trust should ensure 95% of patients attending any A&E Department are either treated and discharged home, or admitted within four hours of their arrival in the department”

Priority for Action target for NI 2010/11

Being seen by a doctor when you are ill and being seen quickly is such an important issue that we set the government a target that no-one should have to wait over four hours when they are in mental health crisis, this mirrors the target the government set themselves as shown above. On attending A&E at the Mater hospital last Autumn one service user told us that he arrived at 6pm and “*sat waiting until 3am*”. The nine hour wait made him feel frightened; he told us “*I was just left there on my own, with my thoughts...if you want to take your own life, there was nobody to go ‘are you alright?’ or ‘can I get you anything?’*”.

0% of people waiting over four hours was a serious target to set, but from our experience, many of the people most in need find it impossible to wait that long in an A&E waiting room. Ensuring that things improve dramatically here could be the difference between life and death for some people in serious crisis.

When we monitored the issue again in 2011, not only had things not improved, they had actually gotten slightly worse with 46% of people in mental health crisis having to wait over four hours before being treated, admitted or discharged.



■ Waiting over four hours in 2010
■ Our target for 2011
■ Waiting over four hours in 2011

Many of those who took part in our research felt it important that people recognise how difficult lengthy waiting times are, with some respondents indicating that it is a factor in determining whether or not they are able to stay until seen by the doctor for assessment. Some people told us that they left because they “*couldn’t take it anymore*”. The issue is also an important one for carers, one told us that when she accompanied her son to A&E she felt like “*they [hospital staff] had no time for him, the waiting time just frustrated him, the onus was on me, the carer to keep him in the hospital*”.

Issue 3

People in mental health crisis aren't always receiving proper follow up care once they leave A&E



BMHRG: Why this issue is important

“People need and deserve proper follow up care so they don't get into crisis again. Without it, things become a vicious cycle.”

Grace - Belfast Mental Health Rights Group

In 2010, 13% of people who had been to A&E in mental health crisis and were in need of follow up care told us that they received a written appointment on discharge.

This means that 87% of people in crisis left without adequate support. To put this in context, for every ten people who went to A&E in crisis, 8 of them left with nothing. A written appointment is something which would keep people linked into services, a “lifeline” as the Belfast Mental Health Rights Group referred to a written appointment within seven days of discharge during their campaign for the Card Before You Leave.

Those who took part in our research felt very strongly about the importance of this issue, indicating that it is not sufficient to ‘walk away with nothing’ in terms of follow up care. One respondent, who had been to A&E in mental health crisis and left without a follow up appointment told us *“I was just given a leaflet about support, but I didn't go to hospital for a leaflet, I went because I needed help.”*

Others commented on the need to get an appointment before you leave hospital, not one that is posted out. A service user who had spent twelve hours waiting to be assessed in A&E told us that when he had asked about a

discharge letter, a nurse told him that it would be posted out to him - this was despite the fact that no one had taken any information about where he could be contacted and the fact that the man had no permanent address. He stated that this had made him feel *“angry and disrespected”*.

Local policy and international human rights law are very clear about appropriate and timely health care.

WHAT DOES HUMAN RIGHTS LAW SAY?

“...health facilities, goods and services must also be scientifically and medically appropriate and of good quality.”

Committee for Economic, Social and Cultural Rights, General Comment 14, para 12 (d)

WHAT DOES LOCAL POLICY SAY?

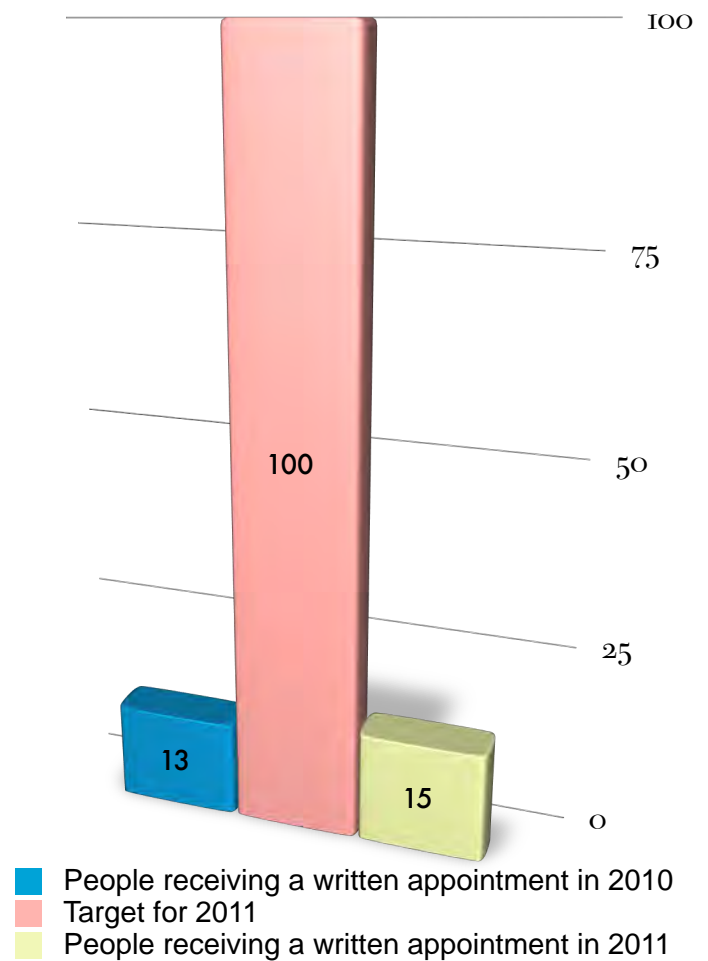
“From April 2009, all mental health patients seen at A&E departments and assessed as requiring further mental health care should have an appointment made with mental health services before they leave the A&E department”

Bamford Action Plan 2009-2011 page 82

The Belfast Mental Health Rights Group have worked since 2009 to ensure that people get the support they need with the creation of a Card Before You Leave appointment system. Since the system’s launch across all A&E’s in Northern Ireland in January 2010, anyone who is discharged from A&E should receive a written appointment card with the date and time of their follow up appointment. Because of this, the group felt that it was essential to set the government a target which would test their commitment and so it was decided that by 2011 no-one who presents in mental health crisis, should be leaving A&E without a follow up appointment.

By 2011, however our research shows that the situation is not improving as quickly as it needs to with only 15% of those going to A&E in mental health distress receiving a written appointment on discharge.

Frustration with not receiving appropriate follow up care is strongly evidenced in our research, many of those we spoke to pointed out how difficult it is for someone in mental health distress to chase up appointments after discharge themselves - receiving an appointment by telephone isn't appropriate, as one respondent commented, *"If there's people feeling like that, they wouldn't answer the phone, they wouldn't go across the road to the doctors"*.



SECTION 2:

What do we mean by participation?

WHAT DOES 'REAL' PARTICIPATION LOOK LIKE?



“Effective provision of health service can only be assured if people’s participation is secured by states.”

United Nations Committee on Economic, Social and Cultural Rights, General Comment No.14

‘Participation’ by service users and carers is fast becoming the new ‘buzz’ word with increasing numbers of policies on service user involvement. The danger is that ‘involvement’ strategies will ‘pay lip service’ to participation without actually promoting it.

International human rights law gives people the right to expect participation in decisions about how governments design and manage mental health services; this participation must be active (people need to be taking part in the agenda setting and decision making not just signing off on decisions made by government), free (people must be voluntarily involved in the decision making process and their involvement must be without hindrance) and meaningful (it must be informed and the outcome must reflect their involvement).

Dr Helen Potts is a renowned expert in this area and she has previously assisted the Belfast Mental Health Rights Group’s campaign for meaningful and effective participation, her work and ours shows that participation requires two things:

1. Arrangements put in place to ensure participation at different stages
2. Capacity building to ensure people have the ability to meaningfully and effectively participate¹

¹ For more see http://www.essex.ac.uk/human_rights_centre/research/rth/docs/Participation.pdf

Issue 4

Do people feel involved in decisions made about mental health services?



BMHRG: Why this issue is important

“A doctor can tell you what its like because he’s read it in a book, we can tell you because we’ve lived it. We live it, we are experts in this.”

Bobby - Belfast Mental Health Rights Group

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.

This is despite the fact that both local policy and international human rights law indicate that participation is essential.

WHAT DOES HUMAN RIGHTS LAW SAY?

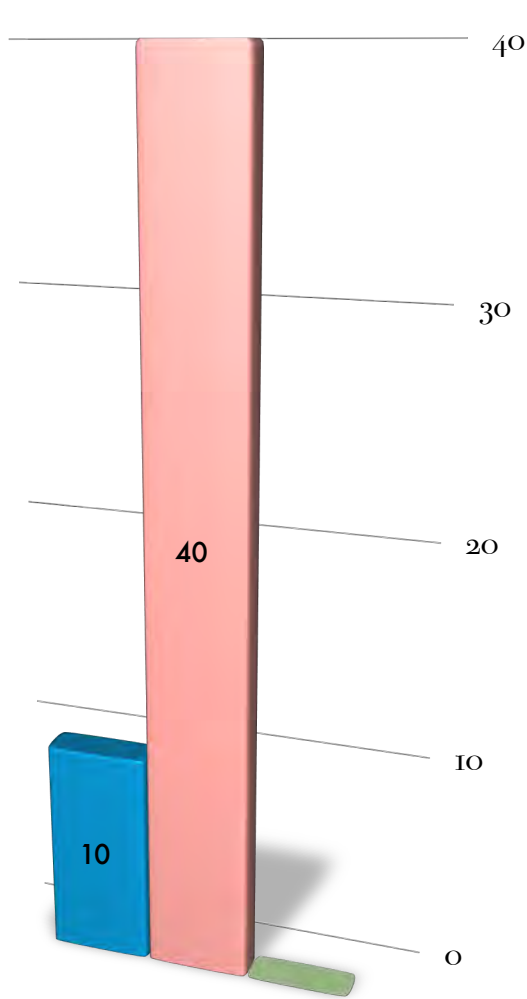
“Under international human rights law, the right of individuals and groups to participate in decision-making should be an integral part of all the policies, programmes and strategies intended to implement the obligation of States parties.”

Committee for Economic Social and Cultural Rights, General Comment 14, para 54

WHAT DOES LOCAL POLICY SAY?

“In planning at a population level, the Health and Social Care Board and its Local Commissioning Groups should ensure that service users and their families and carers are involved in a meaningful way in decisions about mental health”

Bamford Action Plan 2009-2011 page 31



Belfast Mental Health Rights Group set a target that by 2011 40% of those surveyed should indicate that they felt involved in decisions made about mental health services.

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%.

- Those who felt involved in decisions made about mental health in 2010
- Target for 2011
- Those who felt involved in decisions made about mental health in 2011

Issue 5

How difficult is it to get information about how the mental health service works in a way which we can understand and which shows that the most vulnerable are a priority?



BMHRG: Why this issue is important

“They can get away with so much when we can’t see what they are doing. Decisions are being made for people who are very vulnerable, we need to look at them closely so that they are right.”

Kathy -Belfast Mental Health Rights Group

The use of difficult and complicated language can make some documents intimidating to read and not very user friendly. Use of language that is not appropriate acts a barrier to participation. This can be in terms of our own mental health or that of someone we care for, as one person who has been caring for his daughter for forty years indicated in our research, *“I can’t understand all these big words, what I need is some help.”* Crucially, it can also make analysing documents to find out how the health service works, who is in charge, how decisions are being made and where resources are being directed difficult.

Both international human rights law and local policy underline how important it is to be able to access and use information.

WHAT DOES HUMAN RIGHTS LAW SAY?

“In the context of a health system, there must be accessible, transparent and effective mechanisms of accountability to understand how those with responsibilities towards the health system have discharged their duties”

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 p17

WHAT DOES LOCAL POLICY SAY?

The Freedom of Information Act 2000 gave everyone a legal right to seek and receive information in writing from public authorities law. It provides a timeframe for responding (20 working days) as well as listing which exemptions a public authority can use to not provide the information.

To assess how transparent and accountable decision making in mental health service provision is in Northern Ireland, Belfast Mental Health Rights Group monitored the information supplied to them through Freedom of Information requests against not only the local standards under Freedom of Information legislation, but also international human rights standards. By developing and using the following template against which to monitor the responses they received we allocated a total of ten available marks per standard.

	Information we receive should be....	This means that...
1	Accessible	it should be in a language we can understand and available in different formats
2	Effective	we can ask for information on how the health system works, who it provides for and where the gaps are so we can monitor if reasonable questions have been answered
3	Transparent	we can expect that information will be collected and available so that we can monitor whether or not our rights are being realised
4	Timely	we have a right to information within a reasonable amount of time. National legislation gives 20 working days
5	Vulnerable Groups should be included	we can ask for information e.g. statistics broken down by different vulnerable groups e.g. gender, age etc to find out if one particular group's rights are not being realised as they should. National legislation from section 75 of the Northern Ireland Act 1998 gives nine different groups of vulnerable people.

In 2010, the result was 48%.

Belfast Mental Health Rights Group knew from their experience of trying to be involved in decisions made about mental health, however, that information is crucial and so they set the target for 75%.

By 2011, the result has increased only slightly to 50%.

The slight increase masks a fall in scores in terms of accessibility and timeliness. The full breakdown is shown here.

2010 result	Accessible: 7/10	$24/50 = 48\%$
	Effective: 2/10	
	Transparent: 4/10	
	Timely: 10/10	
	Vulnerable groups: 1/10	
Target for 2011	75%	
2011 result	Accessible: 4/10	$25/50 = 50\%$
	Effective: 5/10	
	Transparent: 5/10	
	Timely: 8/10	
	Vulnerable groups: 3/10	

The biggest issue discovered was the lack of information collected amongst vulnerable groups. In many cases, the information is simply not being collected in a way which makes it possible for it to be broken down so that we can see if different groups of people are getting the services they need. This is unacceptable. If attention is not paid to who is experiencing the problem, then no action can ever be taken to make things better.

SECTION 3:

Why is monitoring participation important?



WHY MONITOR? - WHO SHOULD MONITOR? - WHAT TO MONITOR? - OUR MONITORING

Monitoring or measuring participation is the only way to test if it's real and if government are meeting their obligations. Crucially, the monitoring process must be one which is controlled entirely by the people who are trying to participate. It is their monitoring.

The Belfast Mental Health Rights Group have been monitoring how meaningful their participation at the Card Before You Leave Implementation Board since they joined in 2010. Having had previous experience of sitting on Boards, members wanted to make sure that their participation was being reflected properly in decisions made by the Board so they developed a 'checklist' of issues which the Board had to meet to ensure that participation was being made real. Many of these are reflected in the Health and Social Care Board's own strategies on participation. For other groups, the barriers to participation may differ slightly but these are the issues Belfast Mental Health Rights Group chose to measure.

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
	Our expenses were covered

The group has monitored and reported on how the Board met these standards regularly and despite consistent failings there was no improvement for a lengthy period of time. Having decided what the barriers were to participation and notified the Board that monitoring of these issues would take place, the Group's evidence on how these standards was not being met was powerful. In June 2011 the Group wrote to the Chair of the Health and Social Care Board and requested the opportunity to present the evidence of these failings in public. Specifically, they used evidence which showed a failure to meet the first standard in relation to what should happen before the meeting e.g. that the date, time, agenda etc would be made available two weeks in advance. The results are shown in the table on the next page.

Meeting date	Meeting postponed?	Agenda received?	Date agenda received	No. of working days before?	Minutes received?	Date minutes received	No. of working days after?	Did group amend minutes?	Other notes
19/04/2010	No	Yes	15/04/2010	2	Yes	17/06/2010	42	No	start time of meeting changed three times
28/06/2010	Yes	-	-	-	-	-	-	-	-
19/07/2010	No	Yes	16/07/2010	1	Yes	23/07/2010	4	No	
30/09/2010	No	No	email on 29/09/2010 said there was no agenda		Yes	11/11/2010	30	No	
18/11/2010	No	Yes	11/11/2010	4	Yes	14/12/2010	18	No	
18/01/2011	No	No			No				
18/04/2011	Yes	-	-	-	-	-	-	-	-
23/05/2011	No	Yes	20/05/2011	1	Yes	14/06/2011	16	Yes	

- ➔ Between April 2010 and May 2011, **eight** meetings of the CBYL Implementation Board were arranged.
- ➔ 2 meetings were postponed. **[25% of the time the meeting was postponed]**
- ➔ 6 went ahead.
- ➔ The **agenda** was received in advance of the meeting for four of the six meetings; however in two out of four cases it was sent on a Friday afternoon for a Monday morning meeting. On average the agenda is received **less than 2 working days** in advance of a meeting
- ➔ The Board's **terms of reference** agree to abide by participation standards which state that the agenda should be sent out two weeks in advance. Between April 2010 and May 2011 **this never happened**.

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 have arranged for a dedicated member of staff to ensure that the participation standards are being met.

In April 2012, three years after the Group took their seat on the Board, the agenda and minutes were received two weeks in advance of the meeting for the first time ever.

Senior Health and Social Care officials have also indicated that they are keen to roll out the lessons from the Group’s participation into their wider strategies on patient and carer participation and would like to set up meetings so that this can be done. The Group look forward to this important work commencing.

SECTION 4:

What happens next?

LEARNING THE LESSONS



BMHRG: Why this is important..

“This campaign is our journey - what the pitfalls have been, what the gains have been - from it other groups will have the knowledge about how to do it...even the government could learn from it. The evidence is there, if they don't learn, more things will go wrong.”

Bobby - Belfast Mental Health Rights Group member

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.

POOR PARTICIPATION LEADS TO POOR DECISIONS: For example:

1. Failure in simple tasks:

(a) The Board has only recently begun to meet its own standards in terms of sending out agendas in advance of the meeting. Because the Group didn't have the information in advance, they were at a disadvantage when it came to participation.

(b) In January 2011 the group proposed to the Board that a standing item on the agenda should be created to discuss the issue of participation which was

agreed by the Board. However, since no minutes were made, no record was made of this commitment and at the next meeting the agenda did not include this standing item. It has only been in the last three months, following pressure from publication of the monitoring that this has happened.

2. Inconsistent information: The Group has repeatedly asked for Trusts to use templates to show how they are implementing Card Before You Leave. This has rarely been done and it is then impossible to make comparisons about implementation of the scheme across Trust areas which leads to poor knowledge for us and for everyone else - which makes it difficult to identify not only problems but also good practice. Some members of the group have had recent experience of supporting someone through a mental health crisis at A&E, and it is telling that despite our long term involvement in Card Before You Leave, in practice we were still unclear as to what should happen. This confusion is not acceptable.

3. Decisions taken away from the table: Following the Minister's direction that Card Before You Leave should be established and rolled out across Northern Ireland in November 2009, an implementation board was set up. By the time of the official launch in 2010, the definition of Card Before You Leave had changed significantly with some Trusts offering appointments by phonecall instead of written appointments. This decision was not made at or ratified by the Board charged with its implementation. Following extensive lobbying by the group, Card Before You Leave is now being rolled out according to the Group and the Minister's original intentions and all Trusts now give patients a written appointment before they leave hospital. The confusion to front line staff and patients as well as to their carers that this has caused has contributed to a failure to respond to the most vulnerable, over the first 11 months that Card Before You Leave was in operation, as the monitoring shows.

4. Monitoring & evaluation concerns: Ensuring that Card Before You Leave benefits those most in need and delivers the right outcomes requires robust monitoring and evaluation. In March 2010 the Group submitted monitoring proposals and asked for feedback from the Board, this never happened. It was only after pressure from the group that the Card Before You Leave Board

finally had a brief discussion about it at the end of a long meeting in January 2011.

Lessons Learned:

1. It's not enough to have an agreement from government that things will change. we have to keep an eye on them to ensure that the change actually happens. The only way to know if the change is actually happening is to record people's experience.

2. Information is essential. The right information at the right time in a form we can understand is essential to accountability (deciding if decisions are being made properly and ensuring government are doing their job) and to participation (being involved meaningfully in decisions which affect us)

3. If participation is real it will change the way decisions are made. If the way decisions are made changes, the results on the ground will change too. The only way to tell if things are changing is to measure both how involved we are in decisions and if the results for people on the ground is improving.

4. We need to hold government to account for the lack of change for the most vulnerable. Only by participating can we do this. Participation and accountability are two sides of the same coin. Government will only truly change the process and thus the outcome if enough of us demand it!

Patient and Carers Experience at A&E – Research Results 2011: Belfast Mental Health Rights Group

<p>What is the issue?</p>	<p>People in mental health crisis don't have enough information about the treatment they are supposed to receive when they are in distress, and nor do there carers</p>	<p>People in mental health crisis are waiting too long to be treated when they go to A&E</p>	<p>People in mental health crisis aren't always receiving proper follow up care once they leave A&E</p>	<p>Do people feel involved in decisions made about mental health services?</p>	<p>How difficult is it to get information about how the mental health service works in a way which we can understand and which shows that the most vulnerable are a priority?</p>
<p>In 2010 what was the situation like?</p>	<p>only 20% of people who had been in A&E for help when they were in mental health crisis and their carers together told us that they had enough information</p>	<p>45% of people who had been in A&E for help when they were in mental health crisis told us they had waited over four hours before being seen by the doctor</p>	<p>In 2010, 13% of people who had been to A&E in mental health crisis and were in need of follow up care told us that they received a written appointment on discharge.</p>	<p>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.</p>	<p>In 2010, the result was 48%.</p>
<p>What target did we set the government to meet by 2011</p>	<p>By 2011, we said that government should have ensured that 85% of people were satisfied with the level of information they receive in A&E</p>	<p>Being seen by a doctor when you are ill and being seen quickly is such an important issue that we set the government a target that no-one should have to wait over four hours when they are in mental health crisis</p>	<p>By 2011 no-one who presents in mental health crisis, should be leaving A&E without a follow up appointment.</p>	<p>by 2011 40% of those surveyed should indicate that they felt involved in decisions made about mental health services.</p>	<p>Belfast Mental Health Rights Group knew from their experience of trying to be involved in decisions made about mental health, however, that information is crucial and so they set the target for 75%.</p>
<p>in 2011 what was the situation like?</p>	<p>29% of people who had been in A&E for help when they were in mental health crisis and their carers together told us that they were happy with the level of information they received</p>	<p>in 2011, not only had things not improved, they had actually gotten slightly worse with 46% of people in mental health crisis having to wait over four hours before being treated, admitted or discharged.</p>	<p>By 2011 15% of those going to A&E in mental health distress receiving a written appointment on discharge</p>	<p>By 2011 the number of survey respondents who indicated that they felt involved in decisions made about mental health services in Northern Ireland plummeted to 0%.</p>	<p>By 2011, the result has increased only slightly to 50% but there is still a big problem with information not being properly collected about vulnerable groups.</p>

A final note

The Human Rights Based Approach the Belfast Mental Health Rights Group use

The Belfast Mental Health Rights Group's research presented here was carried out as part of their use of the PPR human rights based approach.

The right to health is contained within the International Covenant on Economic Social and Cultural Rights, an international treaty that the UK and Ireland governments have signed up to.

By signing up to this treaty government have promised to respect, protect and fulfill our right to health. A big part of this commitment is that government always have to show that they are taking steps to ensure that things are getting better, and that even if money is tight, like during a recession, they still have to protect the vulnerable. To test if the decisions government are making about this issue would make things better, the group measure how much or how little progress government are making across a number of indicators (we have referred to them as issues here) and set benchmarks which they have to meet (we have referred to them as targets here).

To find out more about the PPR Human Rights Based Approach and how groups can use it, visit www.pprproject.org or contact info@pprproject.org

B M H R G
Belfast Mental Health Rights Group

