

Patient and Client Council

Is Bamford making a difference?

Report from Open Dialogue Mental Health Conference

August 2011

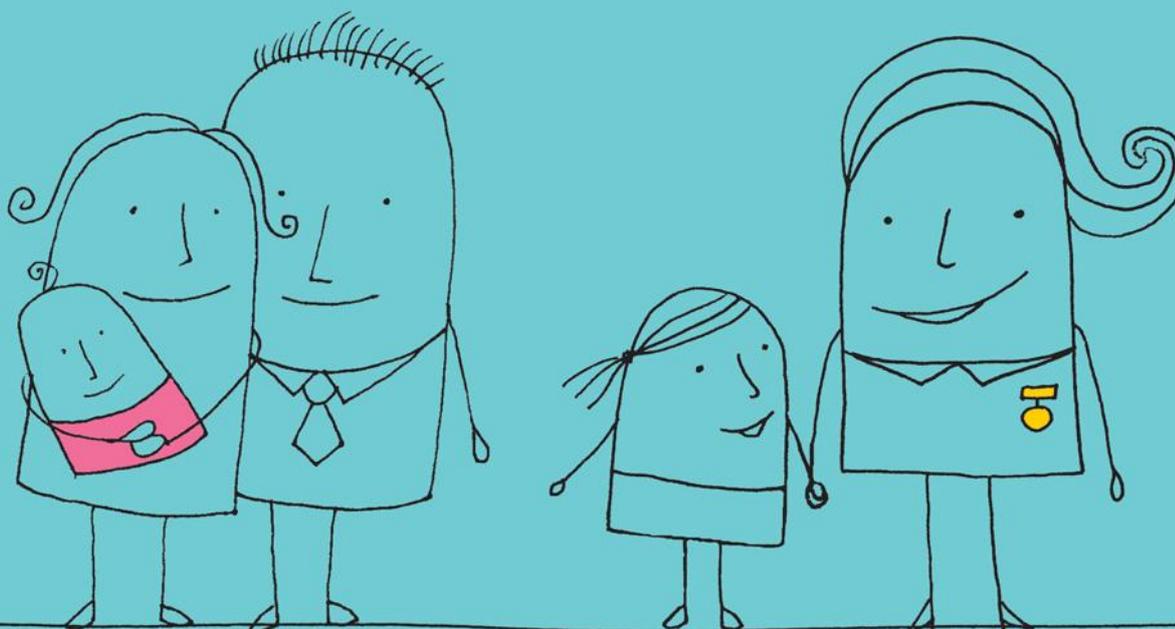


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Foreword

At the end of the Bamford Review of Mental Health and Learning Disability, which had significantly involved service users and carers in its discussions and development of recommendations, the two mental health reference groups, Experts by Experience and the Carers' Reference Group, produced a joint document anticipating the implementation process. It argued that the progress in facilitating service user and carer participation should not be lost and proposed that the partnership forged continue into the implementation, monitoring and evaluation stages. It was their expectation that the processes would become widespread and inclusive.

The notion of partnership, in this context, 'strategic partnership', involves a shared sense of the need for change. It involves addressing how power differentials within the health service might be redressed so as to facilitate meaningful communication. The Bamford Monitoring Group's 'Open Dialogue Mental Health Conference' represents a significant contribution in the development of such strategic partnerships looking at ways to assess if Bamford is making a difference, focusing, initially, on three areas of concern for service users and carers. The proposed principles, guidance and innovative methods for genuine effective service user and carer participation and involvement are of value beyond the confines of this individual conference.

'Making mental health service user involvement effective', the presentation emanating from work in the Empowerment and Social Inclusion Unit of the Mental Health Foundation, brings layers of depth to the thinking that informs the practice of this endeavour here in Northern Ireland. Getting a service user into the meeting was a start, but never enough! The Trialogue, bringing together in equal numbers service users, carers and service providers, offers an opportunity for greater openness of dialogue with people 'taking off their hats' – using first names only and leaving their own territory. One could see the potential for people to hear one another's ideas without prejudice and to experience the value of real partnership. The conference enabled the expression of new and sometimes challenging ideas and the experience

of Dublin City University proponents of 'Open Dialogue' indicates the capacity of the dialogue to become self-sustaining at community level.

The subject matter and scope of the conference have been ambitious. Important messages have emerged, not just concerns, but suggested solutions, regarding, supporting and developing a person-oriented range of facilities and resources in the community; the provision of an appropriate and compassionate range of therapies, interventions and ways of being; and imaginative thinking about action and responsibility when dealing with a crisis. In addition a new method of partnership-working worthy of development and replication has also been demonstrated. However, the overwhelming message emerging from this conference is of the enormous work that must yet be done for Bamford to make a real difference in people's lives. We need to progress from the inspiration generated by this conference to a more widespread and urgent implementation of the Bamford recommendations. Not only do changes need to be made, but they must be seen to be made and more importantly, *felt* in the lives of service users and carers. This group is, ultimately, the group for whom the Bamford Monitoring Group exists and to whom all mental health care services are accountable.

Our public servants and a great many of our public services have a direct impact on, and thus serious responsibility for, the mental health of our entire community. It must be asked whether the groups charged with implementing the Bamford Recommendations and monitoring their impact have been allocated the necessary resources, authority and powers to accomplish this. If the power base has not significantly shifted, the same inputs will naturally only achieve the same old, unacceptable results we have experienced until now. The choice to adequately or inadequately implement Bamford, and the consequent outcomes, is our future.

Thanks are due to all those who contributed their time and experience to making the conference a day to remember.

May McCann and Martha McClelland,
Bamford Monitoring Group Members

Summary

The purpose of this report is to present the key themes arising from 'Triologue' meetings and discussion workshops held at the 'Open Dialogue Mental Health Conference' on 23rd June 2011 hosted by the Bamford Monitoring Group of the Patient Client Council, in conjunction with the Mental Health Triologue Network Ireland.

145 people attended the conference which brought together mental health service users, carers and professionals through the open dialogue process 'Triologue' to discuss the question, 'How will we know if Bamford is making a difference?' People also took part in one of three workshops, 'Support in the community', 'Therapy and Medication' and 'Dealing with a crisis', at which many key issues were raised.

People acknowledge that the Bamford review is a **change process**; while there is evidence that positive changes are beginning to take place, people recognise that more tangible outcomes will take time. People did express their frustration at the slow pace of change and concern that lack of resources and funding may undermine the process.

Service users and carers must remain central to the Bamford review process, including the future planning of mental health services in Northern Ireland.

People would like more information on the range of services and alternative therapies available to them locally, including those offered by community and voluntary organisations. Community based and voluntary mental health services play an important role and it was suggested that statutory services should work with these organisations to support those affected by mental health issues. This is particularly significant because accessing mental health services, especially in times of crisis, remains an issue for some people.

People agree that education and open discussion about mental health have an important role to play in decreasing stigma and discrimination around mental illness and in creating more compassionate communities.

1.0 Background and Purpose

1.1 The Patient and Client Council

The Patient and Client Council provides a powerful, independent voice for people. It has four main duties. They are to:

- listen and act on people's views;
- encourage people to get involved;
- help people make a complaint; and,
- promote advice and information.

1.2 The Bamford Monitoring Group

In 2002 the Department of Health, Social Services and Public Safety (DHSSPS) carried out an independent review of mental health and learning disability law, policy and service provision. It was called the Bamford Review of Mental Health and Learning Disability, now known as the 'Bamford Review'.

Between June 2005 and August 2007 the review produced a series of 10 reports that made over 700 recommendations to improve mental health and learning disability services. It represented a far reaching vision for reform and modernisation of mental health and learning disability services in Northern Ireland. The Equal Lives report (DHSSPS, 2005) focused on reviewing policy and services for people with a learning disability.

In October 2009, the DHSSPS published the report 'Delivering the Bamford Vision: The response of Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability. Action plan 2009 – 2011' (DHSSPS, 2009). This sets out the specific actions that Government Departments and their agencies are committed to take during the period 2009-2011 to improve mental health and learning disability in line with the Bamford Review recommendations.

The Bamford Monitoring Group has been set up by the Patient and Client Council to monitor how changes being made to law, policy and services arising from the Bamford Review of Mental Health and Learning Disability are affecting people and communities.

The role of the group is to find out from people with mental health needs, learning disabilities, parents, carers, family members and communities whether these changes are making a positive difference to them. We want to know if people have experienced any changes to services in their area, if so what has been the effect of the changes on their health and wellbeing. We aim to make sure that the voice of people who have mental health needs, learning disabilities, families and carers is heard and acted upon.

The Bamford Monitoring Project Team of the Patient and Client Council carried out the field work for this project, information about the team is in Appendix 1.

1.3 What is the purpose of this report?

The purpose of this report is to present the key themes and feedback arising from 'Dialogue' meetings and discussion workshops held at the 'Open Dialogue Mental Health Conference' on 23rd June 2011. This event was hosted by the Bamford Monitoring Group of the Patient and Client Council, in conjunction with the Mental Health Dialogue Network Ireland (MHTNI). **145 people** contributed to the discussion and this report is a summary of what people said.

The Bamford Monitoring Group wishes to ensure that the experience of patients, service users, carers and families helps to shape the future of mental health services in Northern Ireland. This report outlines the views of people attending the 'Open Dialogue Mental Health Conference' as a means of informing senior decision-makers in Health and Social Care.

2.0 Our Approach

On Thursday 23rd June 2011, the Bamford Monitoring Group of the Patient and Client Council hosted the 'Open Dialogue Mental Health Conference', in Grosvenor House, Belfast. There were **145 people** attending, including service users, carers, professionals as well as voluntary organisations and community groups.

The conference opening address was made by Mr Edwin Poots, Minister for Health, Social Services and Public Safety. A brief welcome and introduction to the conference was made by Professor Hugh McKenna, Chair of the Bamford Monitoring Group followed by a short address by Dr May McCann, Vice Chair of the group and Martha McClelland, member to set the scene and plant seeds of thought for the day. Several invited guests then gave presentations, including:

*'Putting Recovery At The Heart Of
The Bamford Reforms'* Professor Roy McClelland

*'Making Mental Health Service
User Involvement Effective'* Guest Speaker
Dr Eva Cyhlarova, Head of Research
Mental Health Foundation

'Progressing the Bamford Vision' Maureen McCartney, Department of Health,
Social Services and Public Safety

'What is 'Triologue'?' Dr Liam MacGabhann and Paddy McGowan,
Mental Health Triologue Network Ireland
Project Co-Leads, Dublin City University

Presentations can be downloaded from the Bamford Monitoring Group section of the Patient and Client Council website: www.patientclientcouncil.net

The core purpose of the conference was to bring mental health service users, carers and professionals together through a powerful open dialogue called 'Triologue'. The morning presentations were to 'set the scene' for the 'Triologue' discussions.

Each delegate had the opportunity to attend a 'Triologue' open dialogue meeting and one of the discussion workshops.

3.0 Our Findings

What follows is a summary of feedback from the 'Triologue' sessions and discussion workshops.

3.1 Open Dialogue 'Triologue'

A 'Triologue' is a neutral space where communities can gather to develop their understanding of mental health issues, the challenges of maintaining mental health and to transform thinking on developing better services. It is the creation of a community forum where everyone with an interest in mental health participates in an open dialogue. The question for the Triologue meetings at the conference was:

How will we know if Bamford is making a difference?
... through the changing experiences of service users and carers.

The open dialogue was facilitated by Dr Lám MacGabhann and Paddy McGowan, who are Mental Health Triologue Network Ireland Project Co-Leads from Dublin City University. The meetings were transcribed and summarised thematically by Lorna Ní Chéirín, National Coordinator.

For more information about 'Triologue' and the Mental Health Triologue Network Ireland (MHTNI) visit www.trialogue.co

This section summarises the themes raised by conference participants attending Triologue meetings:

THEME 1: BAMFORD REVIEW IS A CHANGE PROCESS

- **Participants acknowledged that the Bamford Review has created a change process, but that this process will take time to yield tangible outcomes and they recommended communicating that to stakeholders.**

“Yes, it’s planted significant seeds of change and it’s helped us realise what we need to change. But change takes time, and it’s a long, slow journey.”

“Yes, change is coming but by its very nature change is slow. It’s important that the Bamford Review group engage and manage expectations, and that service users and carers have realistic expectations of what change is possible. It’s been very helpful today to hear about ‘phase 1’ and ‘phase 2’ and to realise there is change going on but it’s just not observable yet on the ground to those of us who work directly in service delivery. It sounds like this will change in phase 2!”

“Bamford is a step change. We’re on the way.”

“The principles of Bamford are admirable but perhaps there’s too much expectation as to what’s possible to achieve.”

- **Some participants acknowledged observable change and attributed this to the Bamford Review process.**

“Yes, there used to be no support for carers or for advocates – now we have paid peer advocates and paid carers. Change is happening slowly, we do have a long way to go.”

“Yes, the Bamford Review has linked disability and mental health together and that’s been so helpful in moving the mental health rights agenda forward.”

“Yes, the Bamford Review has highlighted the link between sexual abuse and consequent mental illness – that has meant that our agency has been able to use the Review’s findings to secure funding to offer support services.”

“Yes, the public mentality about mental health is beginning to change. Maybe this is also due to suicide groups and lifeline cards and TV personalities talking about it but there’s definitely raised awareness and now ordinary people are talking more about mental health.”

- **Some participants felt that the slow pace of change was not acceptable and that action, resources, supports and training needed to be put in place urgently.**

“No it shouldn’t take so long, yes we’re talking more, we’re engaging in dialogue but we need action, resources, supports. The real gaps in the services have yet to be filled.”

“It’s concerning that often the people that need to change the most, who work in a certain old-fashioned way, can’t access or are not supported by management to access, training and conferences that could motivate or inspire them to change.”

“No, it’s working too small and too slowly. What’s really changed?”

- **Frustration was expressed at the emphasis on reports and research and there was a request for action and learning through the action process.**

“Let’s please have no more reports, no more reviews – we know what we need. We need resources to meet the identified needs. We need personnel to deliver the services. Let’s get up and running now and we can modify it as we go along.”

“I want to send a message to... (DHSSSPS)... please don’t waste another year launching another review – it beggars belief that we need another report to tell us where the money needs to be spent. Let’s implement what we know now, we don’t need another report, we need grassroots supports.”

“Stop the reports. Use the money to actually help people.”

- **Other participants felt it was too early to make a judgement on whether the Bamford Review is ‘working’ or not.**

“It’s too early to say.”

- **Several participants stated that it would only be possible to judge the success of the Bamford Review by changes in practice ethos and in community attitudes.**

“We’ll know the Bamford Review has worked when we move to a person centred care model, when we follow the person’s needs, not the protocols. The degree to which the Bamford Review can be said to have worked is the degree to which we keep sight of the Bamford principles and values, its spirit and ethos. This is the extent to which Bamford will work.”

“Whether it’s working or not will be seen in community attitudes towards mental health – is there a fundamental change in social attitudes and understanding? What are the key indicators that the principles and values that underpin Bamford review are having an impact?”

- **The importance of keeping the service user and carer voice central to the Bamford review process was noted.**

“There is such value and power of the service user and carer voice. No one knows better what carers and service users need than carers and service users! They need to be at the absolute hub and centre for the Bamford process because they are speaking from the validity of their lived experience, not down from high as some kind of ‘expert’. The role of the service user is to drive Bamford forward and not for Bamford to drive the service users.”

“There needs to be more listening to service users and carers – there’s disjointed, multiple levels of communication. There needs to be more listening – followed by action. We also need more staff to understand what people and carers are going through.”

“Bamford heartens me – I’m so glad to be involved, to have a way to have my voice heard as a service user.”

- **The importance of consulting with service user at an appropriate time was highlighted.**

“Make sure to consult with service users when they’re coherent and articulate, not when they’re in crisis.”

- **The value of engaging in triologue was noted.**

“It’s so important that we have these kind of triologues, and that people hear each other’s experiences and share their knowledge as to what services are out there.”

THEME 2: LACK OF RESOURCES MAY UNDERMINE THE BAMFORD REVIEW

- **Participants expressed concern about the existing lack of resources in the mental health services.**

“I’m greatly concerned about the reduction of hospital beds and services – where are you meant to go when you have a breakdown? What if you don’t have anyone in your family who can care for you?”

“I’ve used the services a number of years ago and recently had cause to use them again. What I noticed was the lack of hospital beds and the difficulties of getting an appointment with the psychiatrist. It appears that nowadays you need to time your mental health breakdown with the availability of beds! That’s not possible, no-one ‘schedules’ their breakdown!”

“Service users are now being told that the phone is the best way to contact key staff members or to get information but then we are left holding for unacceptable lengths of time or can’t even get through – if services are going to give out contact numbers, they need to make sure they are actually staffed!”

“Professionals are even more stressed and frustrated than we are because of the lack of funding and resources – they’re now being asked to do twice as much work with less staff and less time and less money.”

- **Some participants noted that geographical location seems to affect the quality of mental health services received.**

“The mental health services are not uniform in Northern Ireland. The quality and extent of service received seems to depend on your postcode, whether that’s respite for carers, dementia services, counselling services or a psychiatrist that will listen to the patient’s needs.”

“We need to create universal mental health services, not elitist.”

- **Significant concern was expressed that the Bamford Review recommendations would be undermined by the cutbacks in the mental health services and by who is in power.**

“The Review made some great recommendations but we need the resources to back these recommendations up – how can we do this with the current and proposed cutbacks?”

“There is a severe lack of resources in the mental health services, in terms of the current division of resources, and the lack of access to resources. We can’t take any more cuts.”

“The Bamford review is a powerful and strong tool for change but its success will depend on who wields the tool, on how they do so, and on their interpretation of the Review.”

THEME 3: NEED FOR INTERDISCIPLINARY, SPECIALIST, EARLY INTERVENTION and COMPLEMENTARY SERVICES

- **Participants called for interdisciplinary knowledge, services, referral and treatment options to be made available.**

“The reality is that we’re not just talking about mental health – we’re dealing with mental health issues interlinked with complex disabilities or sensory impairment or dual diagnosis – or all of these! We need services that take cognisance of this fact and provide appropriately trained professionals to deal with the complexities of reality.”

“Why is there still such a separation between psychiatry and disability? We have much to learn from the field of disability rights where structures, services and supports enable full participation by citizens.”

“We still need to send people who battle with eating disorders to England to receive specialist treatment – we should have the specialist knowledge here to deal with mental health and eating disorders.”

“The system should train and support professionals to engage in interdisciplinary referrals – I’m a counsellor and I often see people who have already told their story many times to the mental health professionals in the system and then they come to me and we need to start way back at the beginning. Or I may have a client who I think needs specialist mental health care but I don’t know who to refer to... It would be great if we could work together to support clients, not remain in our silos.”

- **The vital importance of early intervention support and tailored interventions as needed was highlighted.**

“Early intervention is absolutely critical in preventing mental ill health worsening. We need to be offering staggered services at the appropriate time of need – not shooting people straight away with the arsenal of heavy medication as a matter of habit.”

- **The cultural context of trauma in Northern Ireland needs to be considered in the provision of appropriate specialist mental health services.**

“The cultural context of mental health in Northern Ireland needs to be acknowledged – the Troubles here have caused untold mental distress and symptoms of that trauma will be seen for generations to come unless we prioritise offering trauma based mental health services.”

- **The inclusion of natural and complementary therapies in mental health services was recommended.**

“Natural and complementary therapies should be on offer to mental health clients – we know what a critical, key role nutrition plays yet the importance of diet and nutrition on mental health is often completely overlooked in the services. “

“Counselling, meditation, yoga and exercise support positive mental health – and they don’t have side effects! Why aren’t these services available as well as the pharmaceutical products?”

THEME 4: NEED TO SUPPORT COMMUNITY BASED MENTAL HEALTH SERVICES

- **Concern was expressed about reducing hospital based services without adequately providing for community care and integration.**

“Are the voluntary sector just being used to replace the community public nursing staff and/or the social workers?”

“Are we building walls in the community around mental health in the guise of community-based care or are we working towards true integration?”

- **Carers need to be listened to and supported as they play a key role in providing effective care in the family and in the community.**

“Carers save the State thousands of pounds by looking after people with mental health illness in the home – carers need to be listened to and supported.”

- **There is a need for information about mental health to be communicated to carers and families.**

“Carers and families need more support to recognise the symptoms of mental health, to know what services are available, and to know how best to support their loved one’s recovery.”

- **Local community mental health support groups can be invaluable sources of support and need to be supported.**

“I slipped through the net and if it wasn’t for my local community support group I wouldn’t be here today. There is great value in identifying with a local group but those groups need some support to keep running. I think we need less consultants and experts and more on the ground groups.”

“It’s all down to the family so where does that leave people without family? Community groups and community services are the lifeblood of mental health.”

THEME 5: NEED FOR EDUCATION ABOUT MENTAL HEALTH

- **The commonality and universality of mental health was given as a rationale for significant education about mental health.**

“We need to educate ourselves and to be educated about mental health because all human beings have mental health issues at some point in their lives – we’re no different.”

- **Participants spoke about the critical need for dialogue and education about mental health to take place in community, educational and workplace settings.**

“Education is so important in the workplace, in the community so we know what to expect if someone we work with or care for becomes mentally ill. We need to know how to respond appropriately, how to support and how to understand.”

“The current education in schools should include mental health as a subject - there is questionable relevance of much of the curriculum to real life after school, why are we teaching our children to name rivers in Africa but not know how to manage distressing emotions? We need to take a hard look at the current curriculum in schools, colleges and universities.”

“We need to involve educators in conversations about mental health – there is fear I think among teachers and public that talking about mental health could result in children and pupils becoming mentally ill!”

- **The value and impact of self education on creating a capacity to care was noted.**

“There is such huge value in information, in educating ourselves; this informs our ability to care.”

THEME 6: NEED TO ADDRESS STIGMA AND TO CREATE COMPASSIONATE COMMUNITIES

- **Tolerance of diversity and open dialogue about mental health was recommended to combat stigma and discrimination.**

“I think a lot of discrimination comes down to how we understand and tolerate diversity. Yes someone else’s behaviour can impact on us emotionally and we need to acknowledge and deal with that but we also need to focus on what we can do to help and support individuals that are struggling with mental health challenges rather than jump and blame and reject that individual. That only worsens their isolation.”

“In order to challenge the oppression of stigma and the history that we have of hiding mental health issues, we need to model openness and not hide mental health

difficulties, we need to be upfront and to refuse to be ashamed, we need to share information and ensure inclusion and discussion of values.”

- **Concern was expressed that workplace discrimination is built into the recruitment process in some sectors.**

“There’s discrimination in the workplace – for example employment forms now ask people if they have ever suffered from mental illness – don’t tell me that won’t affect selection choice.”

- **Participants spoke about the stigmatising effect of language used in the services that can reduce a person to a pathological diagnosis or a dehumanising label.**
- **Participants recommended that service providers use humanistic and person-centred language with awareness to convey respect and to promote recovery.**

“Why is the language of psychopathology used versus the language of mental health recovery and wellbeing?”

“Language can perpetuate stigma.”

“The identity as a service user is a label that can create instant distance from others and misunderstanding.”

- **Concern was expressed over the media’s stereotypical portrayal of people with mental health difficulties.**

“The media perpetuate stereotypes of people with mental illness being dangerous to self and others.”

- **The inter-related nature of social ills and mental health difficulties was raised.**

“The nature of contemporary society is exacerbating mental illness in our communities – there have been radical changes in family structure, technology has fundamentally changed the way we communicate and is leading to alienation from people in many instances. We need to acknowledge the role that social issues play

in actually causing mental illness – whether that’s poverty or domestic violence or childhood abuse or a lack of a significant caring person in someone’s life. Let’s demystify mental illness and start seeing it for what it really is – symptomatic of a greater social mental ill health.”

- **Developing compassion and creating more caring communities was recommended.**

“We need compassion for everyone; we’re all vulnerable to mental health.”

“We need to learn how to care again. We need to engage in dialogue about how we can create a more caring society.”

“I don’t care what you know. I just need to know that you care.”

3.2 Discussion workshops

This section summarises the themes raised by conference participants attending discussion workshops; these were facilitated by Patient and Client Council Staff, with support staff to record feedback and comments made.

People shared their experiences and considered how 'success' can be judged in the following areas:

- **Supporting people in the community;**
- **Therapy and Medication;**
- **Dealing with a crisis.**

Each person attending the discussion workshops was provided with a summary sheet providing an outline of some of the statements and recommendations made in the Bamford Review of Mental Health and Learning Disability in relation to their workshop topic. It was not a comprehensive list, just a few recommendations to stimulate discussion.

Several questions were used to prompt discussion:

- 1) What has been your experience of [*workshops topic*]?**
- 2) Have things changed in this area?**
 - **What / How?**
- 3) Have things changed for the better?**
- 4) How do we identify what people outside this room think?**
 - **How do we identify what people across NI think – the wider experience?**
- 5) What ideas do you have for improvement?**

3.2.1 Support in the community

THEME 1: SERVICE USER PERSPECTIVES

- **Recovery is important for people with mental ill health.**

One gentleman felt that there were three negative avenues for people with mental ill health all of which would compound their problems. These were 1) family break-up 2) Suicide or suicidal intent 3) prison/being sectioned/hospitalization this would increase the risk of substance abuse or self medicating. The fourth avenue which was a positive experience was that to recovery. He felt that in order for this to happen a mixed bag of professionals should be available to help as a lot of people with mental illness just need to talk about their stress or worries.

- **The importance of spending time and listening to people.**

One lady described her own personal experience; she had been feeling unwell again for a period of two weeks and attended for her three monthly appointment with her psychiatrist. She stated that her depression was getting worse along with all of the other symptoms that she was feeling. She said her psychiatrist was extremely rude and said to her *“you are not that unwell because you have attended here today. You are well presented, and you attend [peer organisation]. Therefore you are not unwell keep your next appointment in three months.”* This lady said this is not the first time that she has had problems with her psychiatrist as she often finds her appointments being cut short and feels dismissed and not listened to.

Advocacy works well within mental health, as often many of the people willing to help have been through the same scenarios as people who are mentally unwell.

THEME 2: CARERS PERSPECTIVES

- **Carers want to be listened to, involved, and shown respect.**

It was felt that carers were shown no respect. Carers would like to be identified as experts in their relative's conditions. They do not want to have access to their

relative's confidential information but would like to have more input in providing a full picture of their relative's mental illness.

It was felt that more and more carers are being gatekeepers to their relative's care fulfilling the nursing role.

Carers feel excluded. One lady gave an example of how her family member had to wait for 5 years to see a dual diagnosis practitioner. This had a significant impact on both her relative and the rest of her family.

One lady who has been a carer for 19yrs said that she has seen considerable change over this period of time but there is still room for improvement.

- **Concern was expressed that more support for carers is required, as they are at risk of becoming unwell.**

There needs to be more support for carers as they are at risk of becoming unwell, especially the case if they care for a family member with enduring mental ill health, as carers have no training and it was felt they are very much left to *"sink or swim"*.

"If services do not become available or are not provided to aid carers then they become unwell and may also need assistance with mental health services".

A person from a community organisation felt that there needs to be more support for carer's and that GP's should become more involved with this aspect.

THEME 3: THE IMPORTANT ROLE OF VOLUNTARY AND COMMUNITY ORGANISATIONS

- **The importance of mental health community groups in supporting people.**

One lady said she got most of her support from her community group. She feels that they *"gave me the tools and practical ways of dealing with depression"*. She is still

involved with this group at present, although it is to provide peer support to others who are experiencing the same difficulties as herself.

- **The role that the voluntary and community sector have in making change happen was acknowledged.**

What initiatives/changes had been made within mental health services had come from the voluntary sector and not by the statutory services, where there is no great sense of change.

The voluntary/community sector would appear more flexible and people felt that the statutory sector is much more rigid.

THEME 4: INTERFACE BETWEEN VOLUNTARY AND COMMUNITY ORGANISATIONS AND STATUTORY SECTOR

- **There was an apparent lack of knowledge of options for referral to voluntary and community groups.**

Statutory services need to know what is available in the community. There appears to be tension or a lack of trust between statutory services and voluntary/community organisations.

Statutory services need to become more aware of local community/voluntary organisations and recognise the benefits of referring people to such organisations rather than things becoming habitual.

It takes a long time to get referred onto new services and during this time the GP does not offer information regarding voluntary/community support.

Often voluntary services are not offered by health professionals and people with mental illness are not always able to source these themselves.

A person from a community organisation felt that there needs to be more collaboration from the NHS and they need to make more people aware of the

support that is available to them. Their organisation have been involved with their local GP practices over the last 12-18 months to make them more aware of the work that they do and to try and encourage GP's to refer patients to them. They have found this process extremely difficult as they said GP's were not aware of their organisation, the work that they done and even where they are. GP's are still reluctant to refer patients, although they have seen a small improvement with this recently.

One person currently working for a Health and Social Care Trust stated that people do not always know what is available to them. This Trust runs a focus group in addition to personal appointments with the relevant health professionals. It was found that few people wanted to participate and were reluctant to attend the focus as they said they found it difficult to talk in new groups regardless of the benefits. There needs to be more diverse methods used within the Trust to aid support. One person suggested that social networking sites may be an appropriate way to achieve this, as they bring collective opinions not just the Trusts; the consensus for this was supported within the group.

- **Patients and families feel they need to seek out and find support for themselves.**

A person from a community organisation said they are also having the same problems in that they are not receiving a significant amount of referrals from health professionals. Help from their organisation is being sought out independently by families of people who suffer from mental ill health. People should be made more aware from their health professionals of community/voluntary groups and other sources of help that are available to them.

Many people with mental illness are often left to seek out community/voluntary services independently.

One volunteer in a community group identified that when they did receive referrals they often got a lack of information. She was denied the information which causes increased stress and anxiety for her and clearly had an impact on this person's

involvement in the group. This lady did say that she was aware for the need of confidentiality but felt that because this information was held from her that this impacted on the help that she could give in return.

- **There was a feeling that the statutory and voluntary and community sectors are not collaborating or effectively working in partnership.**

“The NHS and community/voluntary sector are separate entities they do not work in partnership and there is no collaboration between the two. With the community/voluntary sector it is very much a case of people recognising that they need help and seeking it out themselves or with the help of their family.”

THEME 5: ACCESS TO MENTAL HEALTH SERVICES

- **People described the feeling of a ‘struggle’ to access mental health services.**

“It feels like you are struggling all the time to have access to statutory services.”

“It feels like you have to fight for services all of the time you never seem to be given them automatically depending on your needs of course.”

“Support is not always available; this by and large comes down to budgetary constraints.”

One person said *“there is a distinct lack of confidence in psychiatric services.”*

- **There was criticism that services were ‘impersonal’ in their approach to people.**

“Statutory services are very impersonal it feels like they go down through a checklist of questions with you like a tick box exercise, rather than a personal service they need to listen to what we want more.”

“Statutory services over risk assess – This impedes healing, the voluntary sector appear to do this much better.”

“At present the referral process in statutory services appears clumsy and disjointed often having to reiterate personal details many times; this does not instil confidence in service users who are already having difficulty with trusting other people.”

People felt the NHS showed a lack of understanding of their needs. They felt that nurses didn't understand conditions and how they impact on a person's life, they showed a lack of compassion and they identified the need for them to communicate more effectively.

Some health professionals lack social skills, force their own agenda, they should listen more to their patients as they are experts in their own conditions.

- **There was a feeling of going in a cycle, short term fix rather than meeting long terms needs.**

“Home treatment is a short term fix lasting approx 4-6 wks after this time you have difficulty in seeking out services again when you require. You then start the cycle all over again, with visiting your GP waiting to be referred ...”

- **People talked about times of crisis, what is needed, and what are the obstacles.**

“Accident and Emergency is not the correct place for people to attend who are in an acute crisis of mental illness. The environment is too busy, the staff do not have time to provide adequate care, our needs are not met, and we don't feel like we are treated with dignity and respect.”

People said that health professionals do not tackle problems in the early stages, they *“wait until the situation is critical before the relevant referrals are made or there is a crisis at home.”*

The majority of families are happy for their relatives not to be admitted into the hospital even in times of crisis, but they would like more beds available if the need arose as sometimes admitting someone into hospital is unavoidable.

“There is a lack of psychiatric continuity in times of crisis, often meeting 3-4 different staff in the course of your treatment. This has a big impact on the care you receive, as you often have to give the same facts over and over again therefore slowing down what should be a streamlined, straightforward road to recovery.”

- **Service providers talked about the challenges they face.**

“Many people are very negative of the staff within statutory services, they work very long hours doing what they can often outside their remit doing things that they don’t get paid to do; no one recognises this. Staff often become burnt out with heavy case loads of patients.”

It was felt that there was a constant pressure on staff to increase their paperwork, *“if it isn’t written it isn’t done.”* *“This increases the time that we don’t already have due to the large numbers of patients to deliver adequate patient care.”* It was thought that there is no streamlined service or adequate transition of patients’ notes within services either. It is very time consuming and frustrating not only for the patient but the staff also, having to repeat questions to obtain information that should be readily available.

It was said that *“it feels within mental health services that there is an increased focus on human rights and a serious lack of common sense!”*

- **People described their ‘fear’ of engaging with mental health services.**

Patients don’t always tell staff or inform statutory services about the problems with their care, they feel like they are not listened to. If they do speak up they are frightened of being deemed unwell again; they want to be seen as improving, they don’t want to be seen as trouble makers and they do not want to hinder possible treatments to aid their recovery. It is very much a postcode lottery as to what services are available for people with mental illness. It would appear that there is lot

less support available for people living in rural communities. It is very much dependant on different funding for different trusts.

THEME 6: **VIEWS ABOUT BAMFORD AND CHANGE**

There should be more user/carer/staff involvement in services and any changes being made.

“We would like Bamford to ensure that services are available, or that access is available when the person in crisis needs it.”

“What about people who don’t get better under Bamford”, i.e. chronic and enduring conditions that are apparently unresponsive to treatment. In the context of how outcomes appeared to be defined and measured, there would be no such outcomes for these patients.

“What will Bamford do for people in the community?”

Staff within the statutory services said that they helped in the initial stages of the Bamford Report and were disappointed with the funding available for implementation and in many cases with the implementation itself. Due to the way that statutory services function, change is just recently happening within mental health services, many of which are accredited to Bamford. This is not the driving force for their implementation. This has led to a great deal of frustration within the mental health sector an example of this is card before you leave. This has been fought for by a community group for years.

A development worker who has worked in the mental health field for 12yrs, and was initially involved in the Bamford service user group, said that it was a really negative experience for him and some of his peers. He felt that *“service users were only involved for the sake of inclusion”* and that it was *“more of a tick box exercise”*. He also said that service users were disillusioned with possible changes and that they were taking a really long time to be implemented and as a result they became *“burnt*

out and walked away". Although this is the case he said he "can see change starting to filter through now".

THEME 7: STATEMENTS ABOUT IMPROVEMENT FOR THE FUTURE

"Home treatment needs to be flexible to suit the needs of the patient and requires a revolving door approach."

"The statutory system should be easier to navigate, it must be person-centred and should make things easier for people to move on."

"There needs to be a new structure implemented to enable patients to remain in their community as this currently does not exist."

"There needs to be more education in general around awareness of mental illness this should be started in schools or colleges."

"More options of a befriending service as this would provide the much needed support in the community."

The group felt that more training was needed for front line staff as they appeared to have a lack of understanding a lack of capacity and a lack of time for caring. Improving the options of self care was seen as important; health professionals should teach more self help techniques.

It was thought that when mental ill health develops into a crisis that it was much more difficult to get admitted into hospital, therefore this process should become easier. Although this was the case they felt that the hospital model needed to be re-evaluated because *"at present it takes the recovery process away from the patient; you are told what will happen to you, and the partnership between the patient and the hospital is not always apparent."*

“People with mental illness should be encouraged to become an expert in their own condition, to take control of their health professional and have control of their own life.”

It was thought that GP's need to be more aware of the side effects of medication that they are prescribing as these can sometimes compound or exacerbate mental illness.

One support worker gave an example of how she works with adults with learning disabilities with limited or no verbal communication. She felt that this particular client group was given medication to mask their problems rather than dealing with their problems and providing other resources to help.

3.2.2 Therapy and Medication

People were divided on what Bamford has achieved. The majority felt that Bamford has **NOT** been successful with regards to therapy and medication for the following reasons:

- There has not been the provision of therapies for more serious illness, nor the therapists qualified to provide these therapies;
- Cognitive Behavioural Therapy is only suited to those with mild-moderate conditions, but not to those with more serious, prolonged conditions;
- The government is pushing Cognitive Behavioural Therapy because it is cheap and because there are no alternatives;
- There were experiences of individuals having Cognitive Behavioural Therapy withheld and getting tested on a variety of medications before having to access Cognitive Behavioural Therapy. Individuals who shared this experience believed that a combination of medication and Cognitive Behavioural Therapy would have worked best;
- The only change has been in the computerised version of Cognitive Behavioural Therapy “Beating the Blues” which individuals would not recommend. People commented:

“It is like a tick-box survey.”

“It is not suited to all as people do not all have computers.”

“Peoples conditions restrict their ability and motivation to continue the programme through to completion.”

“It would be much more beneficial to speak with a therapist face-to-face.”

- *“Approaches have been reactive rather than proactive; fire-fighting.”*

- *“People are not aware of what is out there, it is not advertised.”*
- *“It takes too long to diagnose conditions, apart from depression.”*

However, there were individuals who believe Bamford has made a difference with regard to Therapy and Medication for the following reasons:

- There has been a significant improvement in community services, with mental health community nurses being responsive 24 hours;
- There is more access to a range of therapies, provided through occupational therapy, nursing and social work;
- There was reference given to Regional Working Groups on personality disorder and an emphasis that these are working well. Although it was recognised that provision has been slow it was emphasised that progression can be seen and that people’s views are being acknowledged;
- *“We are here”*; people acknowledged coming together at events such as the Mental Health Conference as a step in the right direction;

THEME 1: **MEDICATION**

There was the general consensus that GPs are focussing primarily on medication and prescriptions rather than alternative therapies. Individuals believe this has occurred for a variety of reasons:

- **A lack of awareness amongst professionals of what alternative therapies there are.**

“Are we offering all opportunities that can be offered? Do all professionals know what is available? Are we aware of what other professionals do and how do we work together? We need to think about how we carry out our separate roles and the range of therapies available.”

“As an occupational therapist there is an emphasis on psychological therapies instead of medication. Is this one therapy, or all therapies? What are we talking about in relation to therapies?”

- **Not enough information and training being given, particularly to GPs.**

In relation to medication, individuals generally had negative experiences of GPs. It was felt that GPs emphasis is on prescribing.

“No matter what’s wrong they give out anti-depressants. It’s like they’re clueless and just passing out candy. They are illiterate regarding mental health difficulties.”

Individuals feel that GPs have very little training regarding mental health, not at all adequate, and found this surprising given that individuals with mental health difficulties account for 1/3 of their workload.

Individuals feel that it would be beneficial to liaise with universities to ensure training surrounding mental health difficulties is thorough. They believe that this is crucial now as GPs need to prepare for the rise in mental health difficulties within society.

- **Patients and relatives expectations of medication and the desire for GPs to prescribe.**

“It is a frequent reality that patients are seeking medication and relatives put pressure on to GPs to prescribe.”

“I would be cryptic, if not cynical to say that there is too much medication and not enough therapy. This is very difficult to counteract, what with people smuggling contraband into the country. There is a demand for medication.”

“What we need is an understanding of the appropriate role of medication. This means the public’s role and what professionals expect of medication. It is not one thing or the other. Appropriately used medication can be of high value.”

“Illness is something going wrong, sickness is me and the world around me. What is important is the management of this. There is a misunderstanding of where medication can be used.”

THEME 2: ACCESS TO THERAPIES

Individuals have encountered numerous difficulties in accessing alternative therapies. These include:

- **Waiting lists and Criteria**

“There are waiting lists and we are left questioning, what do we do in the meantime. There is more emphasis on the exclusion criteria, how to keep people out of the services.”

“There is the impact of the PFA (Priorities For Action) targets, there is no quality in the system; it’s get seen and get off the waiting list. When people don’t keep appointments it’s that: that is great, get them off the waiting list, we don’t ask why they didn’t make it. In some places they text the appointments out to the ‘hard to reach’ people. It should be about understanding why people didn’t come, not about getting them out of the system.”

- **Lack of therapies and therapists to undertake particular therapies.**

“In relation to eating disorders where medication is not as relevant, there is lack of therapy and type of therapy.”

“There is a lack of alternatives once you are given one therapy. You are accessing limited services.”

- **Inconsistency between Trust areas**

“Access to different therapies can vary. The referral process can vary. Different people have different experiences.”

THEME 3: AVAILABILITY OF MENTAL HEALTH SERVICES

It was highlighted time and again that people are accessing services in England on a more frequent basis, due to the unavailability of such services in Northern Ireland. It was recognised that this is putting financial strains on families and on the government and that services should be based locally and be able to be accessed locally.

“There are currently 8 people going to England for therapy that is costing the government 3 million pounds. We are wasting money sending people to England when we should have services locally.”

“Patients should not be sent to England, there are not the same therapists back here and when people come back if they drift back in to the same problems they require support over here.”

“There has been new thinking around this (basing more Eating Disorder therapies locally) and it is acknowledged that this is the way to go.”

THEME 4: PATIENT EXPERIENCE

“Patients and relatives say ‘we want this fixed’. It takes a long time to get your perception around that it just can’t be ‘fixed’.”

“Working with Patients as an advocate, they ask, where is the therapy? Patients want less focus on medication and more focus on psychological therapy or treatments.”

There is a misunderstanding of ‘therapy’ that it is done to me. People are reluctant to accept that therapy, whatever is involved, is about a person actively engaging and

doing what needs to be achieved. Indeed a therapist is the coach, creating a new environment to explore for themselves what is needed.

“My first experience of psychological therapies was that it took hard work, tears, then I had the breakthrough... it took time. It was a shock to the system because until I was involved I was not aware of the input that would be required. I wanted the psychologist to have a magic wand and it just wasn't like that.”

“As a parent of a child with an Eating Disorder and Personality Disorder we undertook Multi-Family Therapy in England which was extremely useful. It cost about 10 thousand pounds to travel to England every fortnight, and the therapist travelled to Ireland. This therapy needed to be open to all family members as Eating Disorder impacts on the entire family and we needed educated as well.”

“There is an evidence base which is theoretical and highly specific but it does not relate to real life experience.”

THEME 5: COGNITIVE BEHAVIOURAL THERAPY

There was a lot of discussion surrounding Cognitive Behavioural Therapy. The general consensus was that Cognitive Behavioural Therapy is not suitable for everyone, it is more suited to those with mild-moderate conditions than those with more severe long-term conditions.

“Cognitive Behavioural Therapy does work well with one in part, but not others. Cognitive Behavioural Therapy is not the answer to everything and it is questionable how relevant it is.”

“There is no evidence of Cognitive Behavioural Therapy used for people who are quite unwell.”

THEME 6: INPATIENT TREATMENT AND THERAPY

There was a lot of discontent surrounding inpatient facilities. It was agreed that patients are not seeing consultants on as regular a basis as they should.

It is also felt that there are not enough stimulating activities within inpatient units, which is detrimental to patient recovery. It was agreed that activities are crucial toward recovery and that these do not have to mean in depth psychological therapies, merely alternative, engaging activities.

“Patients can be on high doses of medication for years. The GP does not want to rock the boat when consultant is involved. This idea about seeing the consultant regularly is nonsense. People are not seeing the consultant when they are well, it is only when something goes wrong.”

“Consultants have less time to see patients when they are well. The problem is changing the philosophy of thinking. The focus is on getting people back out of the system rather than on recovery.”

“In one centre they do absolutely nothing. I thought (person) was seeing a consultant once a week, in three months they were seen twice. They just sleep, gain weight, are medicated, watched and let out. They are not seeing the consultant.”

“In wards there is the benefits of activities, that if people are actively engaged they can channel their energy.”

“Inspections in wards are seeing people lying about, sleeping, on more meds (medication). Where is the activity? What is there to do when there? There is a focus on risk, it's too risky, there are not enough staff.”

THEME 7: TRANSITION FROM CHILDREN TO ADULT SERVICES

It was highlighted that there are difficulties in the transition from children's to adult services and this is causing individuals and families a lot of stress.

“There are huge problems in that transition period, the 17-18 age bracket, transferring to adult services. I know where one 17 and ½ year old was told by CAMHS that they were only 6 months off their 18th Birthday and were denied any service.”

“That interface transition needs to be better, it is scary for service users and carers. It's a very bad area with no improvement.”

“On paper it's a seamless transference, the reality is very different.”

“There are children who are too young in adult services because there are no beds. Services are not there for children after discharge. In CAMHS you are supposed to be allowed to stay on after 18 if you are doing well, it's not happening.”

“In England there is a team to deal specifically with children at transition, we should have a specific team to deal with this.”

THEME 8: STATEMENTS ABOUT IMPROVEMENT FOR THE FUTURE

Individuals shared the following with regard to what improvements they want to be achieved:

- To have carers opinions valued and their role seen as part of the cure;
- Involving users and carers to be the decision making bodies;
- Through the voluntary sector, involving individuals in decision making, inviting them to meetings – A partnership approach;

- Promoting training;
- Early intervention;
- More professionals appropriately qualified to deliver therapies.
“we need people to deliver therapies”;
- More therapists to deliver therapies particularly for more serious conditions;
- Carers to be given basic training.
“carers need trained about what to say or do, how to talk to the people, a lot of the time it is not explained”;
- Carers assessments to be carried out in all areas as this educates carers; not to be inconsistent amongst different areas and practices;
- Rural areas and access issues to be acknowledged.
“It is difficult for people to get in from rural areas and to access services because of transport and bus timetables, this needs to be acknowledged”;
- More joined up working; cross departmental working, interdisciplinary working;
- More joined up working between statutory and voluntary sectors;
- A greater emphasis on the person centred planning approach;
- Inpatient facilities to be improved.
“Inpatient facilities are not very good and haven’t changed very much. Patients are vegetating with nothing to do and seeing the consultants very little”;

- A greater focus to be given on how to encounter and solve problems within the community;
- A greater acknowledgment of young people as carers.
“There are a significant number of children who are primary carers and who are virtually invisible to services. This must be recognised as they are afraid to ask for help”;
- An increased use of community groups;
- The formation of focus groups;
- Ease of the transition between children’s and adults services for young people;
- G.P.’s to provide more information on Mental Health difficulties;
- The need to demand the funding that Bamford was originally being offered.
“We didn’t get the money we were supposed to get. Is Bamford going to do anything about it? We need to demand this money, there are ways to communicate that we’re worth it”;
- The need to think of alternative approaches.
“We need to think about what we can do that is not attached to money because funds are not available”;

3.2.3 Dealing with a crisis

THEME 1: WHAT IS A CRISIS? DEFINITION AND CRITERIA FOR ACCESSING SERVICES

Whose definition or perception determines what a 'crisis' is? There appeared to be different views on what a 'crisis' is, and that *"no two crises are the same."*

So how are they [crises] 'prioritised'? What if the service user or GP considers it a crisis? *"I felt that I was in need – this was disputed by someone else's professional judgement."*

This led to discussion around the criteria for accessing services in a crisis (access protocols). People spoke about their 'difficulty' accessing admission / crisis services.

"There is a lack of openness regarding the criteria – what are the criteria for accessing services?"

"I had a quick risk assessment and then I was told I didn't meet the criteria. Risk assessment was not thorough enough."

"A timely response to crisis is needed, not 'you don't meet the criteria'." People with experience of services said that family and friends were thought to be more useful in former crisis situations.

"Professionals are governed by protocols and criteria – this makes us poor listeners."

One person described a negative experience of *"an absolute judgment of a single professional (CPN), even though they were presented with a GP letter which would have better informed their decision."*

There was discussion about when does a crisis NEED the input of mental health services; most are resolved without mental health services.

THEME 2: SUPPORT DURING A CRISIS

- **Personal experiences of people during a crisis**

A few people discussed their *“frustration”* as it was *“almost impossible to access services.”* One person said she was assessed and *“told I definitely needed hospitalised, then told there is no bed.”*

There was the feeling in the group that sometimes hospital is the only route, as community support is not always there. Concern was raised about access to beds, and that the numbers of bed may be cut in future. *“There is a need for better community support if more beds are cut.”*

People talked about the history of people *“being removed and hospitalised in a time of crisis.”* There is now an *“expectation created around going to a hospital bed in times of crisis, which has created an association between mental health recovery and hospital”*. *“Crisis services need to be complimented by appropriate and adequate community services.”*

There was concern about *“taking away the safety net of being able to go to the hospital when you need to.”* *“Sometimes life at home really isn’t good and a person could disclose instances of abuse / bad treatment received in the home. This would be much more difficult to talk about in the home setting and much easier in the safety of a hospital.”*

- **Family support for individuals in crisis was very important, and the effect of crisis on families was discussed.**

Family members feel that they are the crisis support. However, service providers do not always talk to families even with the consent of the individual. *“Families are left to deal with it.”*

“Individuals say ‘I don’t want to be in hospital’ this is ok if there is good family support/ professional support.”

“But some families say that they can’t cope anymore with the 24/7 care of family members especially social situations which have precipitated their crisis.”

The effect on families was made clear *“families are in crisis as well as the family members.”*

“Carers do a great job out of love. In times of crisis, it’s not fair on them. Nurses in hospital can go home, carers are at home.” There is a need for a professional to support the caring role.

THEME 3: PARTICULAR SERVICES / STRATEGIES

How long is a crisis? Does it last long enough to have adequate response, or is it by definition immediate and transitory? People in the group thought that there was a *“lack of support mechanisms in place for crisis situations”*.

- **People described the immediacy of a crisis and the need for help right away.**

“When problems arise after follow up (from hospital), someone will provide a number to contact if you need help and there is no reply or they don’t get back quickly enough to you.”

It was felt that there is a real problem if someone is dealing with a crisis on a Friday evening and; there are no services available until a Monday morning. *“Getting help on a Friday night is almost impossible.”*

One person described a positive experience of the Home Treatment Team 24 hour phone service. *“It helped me from going over the edge.”* However, recently this service changed to an answering service which he didn’t like.

- **Is access 'different' for people inside and outside the mental health system?**

“There is a need for existing service users to have easier access to services when in crisis. There are difficulties seeking help when in crisis e.g. having to tell another mental health professional about your history / condition when this information has already been shared previously.”

“There are two distinct groups who seek crisis services, those with (a) a diagnosed mental health condition and those (b) without a diagnosed mental health condition who present with complex psychosocial issues/ drug related issues. There is a huge gap between (a) and (b).”

One person asked *“if it’s a reactive/ social crisis instead of a diagnosed mental health condition where do you go for help?”*

It was thought that *“it’s not necessarily harder to get an individual without a diagnosed mental health condition assessed but there is a lack of services to refer them onto after assessment.”*

- **People talked about Crisis Contingency Plans and Recovery Action Plans.**

“It’s ok to have that plan in place but in crisis the whole plan goes out the window.”

“Others see me in crisis, I don’t see it myself. Now I have an appointed person as part of my Recovery Action Plan to convince me I’m in crisis – I still resist seeking help.”

There was also discussion about Care Plans, and that much of the same information about crisis and recovery should be in Care Plans – Crisis Contingency Plans and Recovery Action Plans should accompany the Care Plan.

People also considered Advanced Directives / Statements important and felt that both service users and staff should be educated in the use and role of these.

THEME 4: WHAT IS NEEDED TO SUPPORT PEOPLE IN CRISIS?

- **People talked a lot about the need for a place of safety, particularly in relation to suicide and self harm. What needs to happen to help the situation.**

People felt there is a need for a short-term safe place, 24 hours crisis service. *“We need a sanctuary, even for hours”. But “what would a safe place be?”*

There was a discussion about crisis houses, and a place outside of one’s own environment. The landlord/ landlady scheme in England was discussed as *“very successful in offering a temporary place of sanctuary. It is like a ‘B&B’ and major benefits include the long term friendships which develop there.”*

There was discussion around *“expectations”* and what can be done to help people. *“There is no predictive test for suicide. We can only say ‘at this point in time’ – this makes things difficult.”*

There was discussion around what was the cause of suicide? *“Mental health isn’t the main issue, there are many other factors. Mental health services are sometimes important but for ‘personal crises’ mental health services are not always appropriate. What else do they need? How do we support them?”*

People suggested the need for separate suicide services, *“not to have them thrown in with mental health.”*

- **The need for longevity of care and strong therapeutic relationships.**

It was thought to be important to build and maintain therapeutic relationships, *“building a good rapport with CPN”.*

Often individuals can see many mental health professionals. In times of crisis it was thought to be particularly important that someone known to the individuals sees and

assesses them – that way the *“appropriate care can be given at the appropriate time.”*

- **The need for public conversations around self-harm and suicide. Mental health services do not have the answer – dialogue suggested solution.**

The group agreed that *“there needs to be a conversation around crisis services. Where should the solutions come from? Mental health services are not always the answer. In fact they could exacerbate the problem. It might not be a mental health issue – more situational crisis.”*

People discussed *“when does a crisis enter into the mental health arena?”* It was thought that there was a need to look at community / family resources to cope with a crisis. Again it was emphasised that because crisis is very individual, *“support has to be wider than mental health services.”*

“Better mental health services are not necessarily the answer.” *“There is “no one easy answer – its likely to be an accumulation of things”.* Again reiterating that crisis, by its very nature, has no one solution.

There needs to be a community level discussion about these issues and about family and individual responsibility. The need for all Government Departments to get involved and be committed to tackling the issues was emphasised.

- **People gave their views on how things have changed**

Someone asked *“Why take money out of mental health?”* There are *“less beds, and no community resources.”*

“There are people who fall through the net, young people, people who use drugs and alcohol, there are real barriers to accessing services.”

THEME 5: EDUCATION AND AWARENESS RAISING

- **Education and prevention were emphasised to build the skills within people to cope during a crisis**

The group discussed 'social distress' as part of crisis and the challenges families are having to face e.g. 18 year old children on drugs. It was thought we need to raise awareness and provide parents with strategies to cope. *"Strategies are needed to stop young people falling into addiction."*

People thought that *"there is a shift towards prevention/ early intervention re: drug addiction. But resources need to be shared with those who need continuous support throughout their addiction."*

"As a professional I would love to be doing preventative work but I am too busy 'fire fighting' every day. I want to see that community growing, families and services in that community can't do it on their own."

"Educate people within school about mental health. Adults are told to look out for the danger signs but young people are not educated enough."

"Young people think 'not me', no one wants to think it could happen to them."

"Everyone identifies with the advert 'about the masks' it is a good example of how we get mental health in the forefront."

4.0 Conclusions

The Bamford Review of Mental Health and Learning Disability set out a vision for the future development of mental health services in Northern Ireland. This conference was a significant opportunity to bring people together in an open forum to discuss mental health, share experiences, and identify if the vision is being realised.

Overall people acknowledged that the Bamford review *“planted seeds of change”* and has begun to make a positive difference for people with mental health problems, evidenced primarily by the introduction of paid peer advocates and carers in some areas of Northern Ireland.

However, many people expressed their **frustration at the slow pace of change** and the long way yet to go. A lack of resources and worries about the impact of potential cut backs were also a key source of concern.

Access to mental health services continues to be an issue for people. Developing support in the community particularly in light of the reduction of hospital-based services is considered important. Accessing services during a crisis is still thought to be difficult and it appears that there are barriers created in relation to the ‘criteria’ set around accessing services. It was generally believed that there is a great focus on medication rather than alternatives and access to therapies was considered difficult.

The important role of carers was acknowledged throughout the conference. The need to support, listen to and involve carers was emphasised.

Another recurrent issue was the vital role of voluntary organisations and community in terms of supporting individuals and families, and making change happen. It was highlighted that greater collaboration and partnership working is necessary to improve the interface with the statutory sector. Linked to this is the need for better information and advice regarding services and local community resources available.

Education and awareness raising about mental illness and mental health was thought to be an important step in reducing stigma and discrimination around mental illness and also in helping to create more caring communities and society.

Finally, the importance of keeping the service user and carer voice central to the Bamford change process was continually reinforced, as “no one knows better what carers and service users need than carers and service users”.

A true reflection of whether all of the Bamford changes are making a difference is whether or not there is a positive impact on the lives of people who have experienced mental health difficulties, carers, families and supporting communities.

5.0 Recommendations

The outcomes of the dialogue sessions and discussion workshops at the Open Dialogue Mental Health Conference provide an insight into how mental health services are changing, and point towards key issues that need to be taken forward. Therefore, the Bamford Monitoring Group recommends that:

- The Health and Social Care Board should review the adequacy of the range of community-based mental health support services, both from the statutory and voluntary and community sectors;
- The Health and Social Care Board should prioritise the implementation of the NICE guidance entitled “Common Mental Health Disorder: identification and pathways to care” and commission a range of therapies which provide alternatives to medication;
- The Health and Social Care Board, in collaboration with Health and Social Care Trusts, voluntary organisations and community groups should address the need to provide a source of information and advice on available mental health services, and how to access this support;
- The Health and Social Care Board should directly involve service users and carers in the implementation and evaluation of the psychological therapies strategy;
- The Department of Health, Social Services and Public Safety should address the issues raised in this report when developing the phase 2 Bamford Vision action plan for the period 2012 – 2015;
- The Interdepartmental Group, and the lead Department of Health, Social Services and Public Safety should report on an ongoing basis to the public about how the Bamford Vision is being achieved;

- The Health and Social Care Board should prioritise commissioning of services to support people during a mental health crisis. This should include 24 access to a place of safety.

The Bamford Monitoring Group would reiterate the Bamford principles that the service user and carer voice is central to the future planning, commissioning and delivery of mental health services in Northern Ireland. In order to achieve this, the Bamford Monitoring Group believes that the 'open dialogue' approach should underpin the evaluation and monitoring of progress

6.0 References

DHSSPS (2009) Delivering the Bamford Vision: The response of Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability. Action plan 2009 – 2011. Belfast: DHSSPS (October 2009).

DHSSPS (2005) Equal Lives: Review of Policy and Services for People With a Learning Disability in Northern Ireland. Belfast: DHSSPS (September 2005).

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