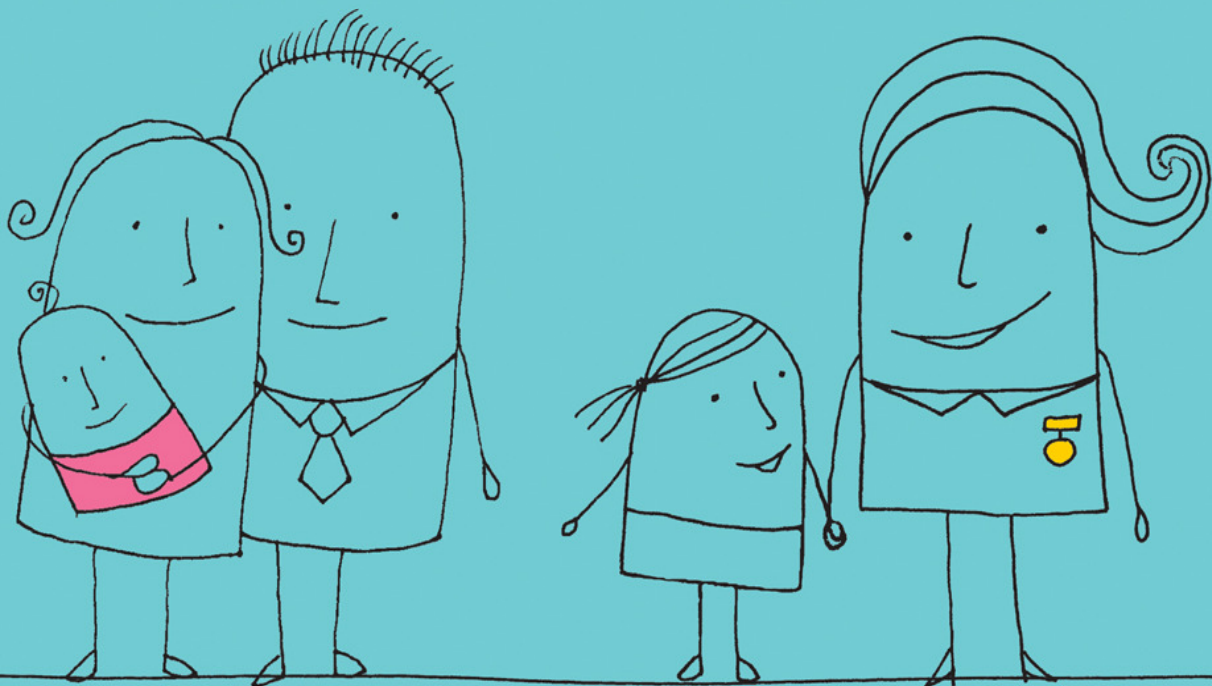


Patient and Client Council

Annual Report of the Bamford Monitoring Group

August 2011



Your voice in health and social care

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Foreword

It is vital that people with a learning disability and those who experience mental health difficulties have the opportunity to tell decision makers about their actual experience of health and social care services.

The focus of this report and the related work of the Bamford Monitoring Group is to understand whether or not the implementation of the Bamford Vision is making a difference. Service users tell us it is making a difference but decision makers and all those with a responsibility to improve the lives of people with a learning disability or mental health problem need to continue to work together to accelerate delivery of the services and benefits which underpin the Bamford vision.

To shape this report, approximately 2,000 people and over 200 groups and organisations contributed in various ways, including: workshops, focus groups, surveys and on a one to one basis. We are privileged to have the input of so many patients, clients, carers and families and thank them for their time and commitment.

As our new Executive finalises and begins to deliver the next Programme for Government in a difficult public expenditure context, we would call on all Departments to prioritise the implementation of the Bamford Vision. This report reflects the ongoing role of the Patient and Client Council to give patients, clients, service users and carers a voice and work to make a positive difference for all concerned.

Yours sincerely,



Professor Maureen Edmondson
Chair, Patient and Client Council

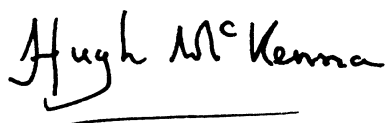
Welcome

This is the second annual report from the Bamford Monitoring Group. Once again, a number of initiatives have been undertaken in relation to the Bamford recommendations. These have arisen from discussions and feedback with service users, families and carers.

It has been estimated that one in four members of our population experience a mental health problem at some time in their lives. This costs the economy billions of pounds in loss of revenue and in the provision of services and benefits. Similarly, learning disability affects several thousands of people in Northern Ireland. Professor David Bamford and his team recognised that the many years of under investment disadvantaged people with mental illness and learning disabilities, their families and carers. At a time when finances are under pressure it may be tempting to reduce spending in these areas. This would be a mistake not only for Northern Ireland's economy and society but for the health and wellbeing of a substantial portion of our population.

The Bamford Monitoring Group has achieved many successful outcomes in its short history, and gathered evidence to prove that focused investment in service provision can have beneficial effects on people's lives. The Bamford Monitoring Group will continue to listen to and act upon the views of service users and their carers. I have no doubt that this will continue to influence, promote and enhance health and wellbeing for the most vulnerable in our society.

Yours sincerely,

A handwritten signature in black ink that reads "Hugh McKenna". The signature is written in a cursive style and is positioned above a horizontal line.

Professor Hugh McKenna
Chair, Bamford Monitoring Group

1.0 Summary

This has been a busy year for the Bamford Monitoring Group and its small project team. This report details the views and experiences voiced by hundreds of people across Northern Ireland who have mental health problems, learning disabilities, parents, carers and family members. It represents a significant body of evidence upon which to draw conclusions and make recommendations regarding the impact the implementation of the Bamford vision is having on those who use and rely upon mental health and learning disability services.

Across the projects a number of themes and messages recur. These include the following:

- Generally, people recognise that the Bamford Vision is beginning to make a positive difference to their lives. However, there is frustration with the slow pace of change.
- People are concerned that funding and the other resources necessary to realise the Bamford Vision may be reduced due to the financial cutbacks.
- There is a need to address, at regional level, the major deficit in the provision of advice and information services for those who use and rely upon mental health and learning disability services. Consideration should be given to the development of a model similar to those in Great Britain such as NHS Choice or NHS 24.
- People with mental health needs, learning disabilities, parents, carers and communities want to be involved in the planning, design, delivery and evaluation of services in Northern Ireland.
- To date there appears to be a considerable lack of interdepartmental working on realising the Bamford Vision. This has the potential to be a major detriment in the delivery of essential services and cause stress to individuals, families and carers.

The work of the Bamford Monitoring Group does not end when this report and the associated documents referenced throughout are published. The next important step is to follow up on the recommendations made with the relevant Government Departments, agencies and organisations, and advocate on behalf of the people of Northern Ireland who use and rely upon mental health and learning disability services.

Several key projects are ongoing and due for completion in March 2012:

- Resettlement from learning disability hospitals
- 7 day follow up after hospital
- Card Before You Leave scheme
- 'Beating the Blues'

There are brief details of these in section 6 of this annual report.

The Bamford Monitoring Group are in the process of prioritising future work streams beyond March 2012, based on learning from the work throughout the year and areas identified by people with mental health needs, learning disabilities, family members, carers that have shared their views and experiences with us.

The Bamford Monitoring Group remains committed to channelling the voice of people with mental health needs, learning disabilities, parents, carers and communities to senior decision-makers across Government. In doing so, its role is to influence the shape and direction of mental health and learning disability law, policy and services in Northern Ireland into the future. This work continues.

2.0 Introduction

The Department of Health, Social Services and Public Safety, Health and Social Care organisations, in partnership with other Government Departments and their agencies have been tasked with making changes to mental health and learning disability law, policy and services in Northern Ireland. This is guided by the recommendations set out in 'Delivering the Bamford Vision' (DHSSPS, 2009).

The Patient and Client Council established the Bamford Monitoring Group to identify whether these changes are translating into improvements in services and better outcomes for the people of Northern Ireland. It is essential to know if the Bamford vision is becoming a reality and making a positive difference for people in Northern Ireland.

This report presents a summary of the work of the Bamford Monitoring Group for the period September 2010 to August 2011. It is the second annual report of the group, for more information please visit the Patient and Client Council website www.patientclientcouncil.hscni.net

3.0 Bamford Monitoring Group Members

Membership of the Bamford Monitoring Group has expanded since the last reporting period.

Five new members joined the group in July 2011; they were recruited following a 'Call for New Members' sent through the Patient and Client Council membership scheme. These appointments were made using a robust and systematic application and interview process.

The Bamford Monitoring Group currently has **19 members** with three people 'in attendance' at meetings. There is now a greater representation of members who have mental health needs, learning disabilities, parents and carers than Patient and

Client Council Board members and staff. This is a significant development and recognises the importance of the voice of service users and carers.

The group is chaired by Professor Hugh McKenna. Dr May McCann is vice-chair and Miss Gillian McMullan is Project Manager. A list of all group members is in Appendix 1. An outline of the Bamford Monitoring Project Structure is in Appendix 2.

The Bamford Monitoring Group reaches out to people across Northern Ireland to capture their views and experiences. This is done through, conferences, workshops, focus group discussions, one to one sessions, surveys, all of which are outlined in greater detail throughout this report. An important forum for communicating and engaging with the public is through the Patient and Client Council membership scheme.

As of 31st July 2011 there are **2,612 members** in this scheme. Of this total, 1,151 individuals and 197 organisations have indicated an interest in mental health and learning disability. This valued resource can be surveyed for views and experiences or become more actively involved in the work of the Bamford Monitoring Group. Further details of the membership scheme can be found in Appendix 3 and through the Patient and Client Council website: <http://www.patientclientcouncil.hscni.net/get-involved>

4.0 Our Work

In August 2010, the Bamford Monitoring Group commenced work on a number of priority monitoring projects. These were chosen from the actions arising from 'Delivering the Bamford Vision' (DHSSPS, 2009).

A summary of the significant findings from our work this year are outlined below:

4.1 My Day, My Way

The 'My Day My Way' project has given people with a learning disability the chance to voice their opinion on how they spend their day and the range of day services and day opportunities available to them.

A total of **1,190 people** with a learning disability, parents, carers and family members took part in this project; **874 people** participated in small discussion groups at day facilities and centres, **120 people** attended the 'Our Stories' conference, and a further **196 people** attended local 'Our Stories' workshops across Northern Ireland.

The **majority of people** with a learning disability **said they were happy with how they spent their day** and whilst they raised some issues and concerns they had many positive things to say about both day care services and 'day opportunities'.

The **most positive response** came from people who have **variety in their week** and divide their time between work, college, social enterprise, work skills training, drop-in or day centres.

However, the concept of choice seemed to be difficult for people with a learning disability. While **most people** felt that they had a **choice of activities** when at the day service or centre they attended, **few identified** that they had a **choice in where they actually spent their day** or were aware of the full range of options available to them.

This is extremely important as having **real choice** means knowing the range of day opportunities that are available locally and being able to choose what you want to do. This **does not seem to be the experience of most people** with a learning disability we spoke to.

Some important themes emerged from this project:

- There is an urgent need to fill the '**information gap**' regarding day opportunities and day care services. On many occasions people with a learning disability, parents, carers and family members said they were not aware of what options are available in their local area.
- People with a learning disability really enjoy college; however a common concern was the **lack of new educational courses**.
- Working and **paid employment** are very important to people with a learning disability, parents and carers. People without a job frequently said they would like to work, and those with a job said they would like to work more hours.
- Some felt that job opportunities available to people with a learning disability were limited. However, people were concerned that being paid and working more hours would **affect benefits**.
- Many parents we spoke to were extremely concerned about the future, particularly the **transition** from children's services to adult learning disability services. Planning and preparation for next steps after school and information on the options open to their children was essential, *"the future is around the corner"*.
- Parents said that **access to key services** such as speech and language therapy and occupational therapy was problematic; this needed to improve.

- People with a learning disability and parents both stated that they were concerned about staffing levels, transport and the reduction in the number of outings from day centres.
- There is a clear call for a **person-centred approach** to day care services and day opportunities, planning around the needs of the individual.
- **Advocacy** groups and opportunities for people with a learning disability, parents and carers to share their views, get involved and contribute to decision-making about their services are important to them.
- Parents felt there was a lack of opportunities for people with **severe and profound disabilities** and those with **challenging behaviour**. A further piece of work is required to specifically focus on gathering the views and experiences of individuals, parents, carers and family members regarding the provision for and needs of this group.

It is clear that in some areas changes to improve day services and day opportunities are in progress. However, more needs to be done to inform people about the options available and to provide them with the support they need when making choices. It is important that the development of day opportunities continues so that people with a learning disability can realise their potential.

The Bamford Monitoring Group recommends that the following actions are taken to address the issues raised in the 'My Day, My Way' report:

- The Department of Health, Social Services and Public Safety should further develop day services and day opportunities regionally.
- The Department of Health, Social Services and Public Safety should work in collaboration with other government departments to identify a clear post-school pathway for people with a learning disability including all the options for education, training, work and leisure that are available.

- The Department of Health, Social Services and Public Safety should work in collaboration with the Department of Education to ensure there is a clear pathway and an early initiation of transition planning.
- The Health and Social Care Board and the Health and Social Care Trusts should develop information and advice service regarding day opportunities and day care services provided for people with a learning disability in Northern Ireland.
- Health and Social Care Trusts should develop advocacy groups for people with a learning disability and create a means to involve and communicate meaningfully with parents and carers on a regular basis.
- The Department of Health, Social Services and Public Safety should liaise with the Department for Employment and Learning to take steps to involve people with a learning disability in developing a range of new further education courses for people with a learning disability, that maintain a focus towards preparation for work, independent living and some leisure options.
- The Department of Health, Social Services and Public Safety should liaise with the Department for Employment and Learning to create further job opportunities for people with a learning disability.
- The Department of Health, Social Services and Public Safety could liaise with the Department for Social Development to address the concerns raised in this report in relation to paid work and benefits for people with a learning disability.

Further details of the day opportunities priority monitoring project and its findings are in the '**My Day My Way**' report. This can be accessed via the following link

<http://www.patientclientcouncil.hscni.net>

4.2 Respite (short breaks)

The respite (short breaks) project gave people with a learning disability and the parents, carers and family members of people with a learning disability and dementia the opportunity to share their experiences of respite (short breaks) and to report what changes they have seen in the provision of respite.

Findings in the report are based on **417** responses to a regional respite (short breaks) survey, and the views of **196** people with a learning disability, parents and carers who attended 'Our Stories' events.

- The clear message coming from parents, carers and families of people with a learning disability and dementia is that **respite is an essential service** and is really valued.
- Most people agree that, **if and when** they can access it, respite is a good service. However, people said that the respite services across Northern Ireland could be improved with **greater availability** and **more respite facilities** in local areas.
- People are aware that respite allocation is limited because demand is high and resources limited.
- When asked if respite (short breaks) have changed over the last five years the most frequent response from parents, carers and family members across Northern Ireland was that things have '**stayed the same**'.
- In the Northern and Western Trust areas some people believe that there is a shortage of respite facilities in their area and no budget locally to provide extra places. The majority of participants who were from the Northern and Western Trust areas felt that they have not received sufficient respite over the past 12 months.

There are a number of areas where parents and carers said that respite services could be further improved.

- They would like **more respite options** and more alternatives to residential or nursing home accommodation. Again, parents and carers who lived in the Northern and Western Trust areas felt that there was a distinct lack of respite options available to them locally.
- People need more **information on the respite (short breaks) available** in their area and advice on how to access these services.
- Many family members and carers (42%) were **unaware of Carers' Assessments**. Of those who have had a Carers' Assessment, some are still **unsure** if it has made an improvement to their respite (short break) provision.
- People said there is a **lack of information** about **Direct Payments**, and some difficulty in accessing them.
- Many people said that the respite (short break) booking service was good, well organised and worked for them. However, there was a view that there could be greater flexibility around advanced bookings and confirmation of dates.
- Most people said that respite was very accessible; but transport to and from respite (short breaks) appeared to be problematic for some who lived in more rural areas.
- Whilst there are fewer families caring for more than one person, the specific issues facing such families are particularly challenging. There appears to be a lack of co-ordination and communication between children and adult services to accommodate the needs of these families.

- Some parents and carers are worried about the transition of their children to adult services, as they are concerned that their son / daughter would receive fewer respite (short breaks) in adult services.
- Most people with a learning disability said there was nothing bad about respite (short breaks) and they would not change anything, except that they would like **more breaks**.

The Bamford Monitoring Group recommends that the following actions are taken to address the issues raised in this report:

- The Department of Health, Social Services and Public Safety should further develop and expand the provision of flexible respite (short break) services regionally.
- The Department of Health, Social Services and Public Safety should facilitate easier access to Direct Payments for respite (short breaks).
- The Department of Health, Social Services and Public Safety should develop new regional information regarding Direct Payments and Carers Assessments which is accessible and available to all.
- The Health and Social Care Board should continue to influence the uptake of Direct Payments and Carers Assessments regionally, by setting challenging targets for the next commissioning period and closely monitoring achievement of these.
- Health and Social Care Trusts should provide clear information about respite (short breaks) and the process for booking for people in their area. This should include details about family contribution towards the payment of respite (short breaks).

- Health and Social Care Trusts should ensure that all families in their area are informed about and offered the opportunity to access Direct Payments and Carers Assessments.
- Health and Social Care Trusts should ensure that there is greater co-ordination and communication between children's and adult services to accommodate respite (short breaks) for families who care for more than one relative.

Further details of the respite priority monitoring project and its findings are in the '**Respite (short breaks)**' report. This can be accessed through the following link <http://www.patientclientcouncil.hscni.net>

4.3 Is Bamford Making a Difference?

In June 2011, the Bamford Monitoring Group hosted the Open Dialogue Mental Health Conference, in conjunction with the Mental Health Dialogue Network Ireland. The report 'Is Bamford Making a Difference?' presents the key themes arising from this event.

In total, **145** people attended the conference including mental health service users, carers, professionals, as well as voluntary organisations and community groups. This was a significant opportunity to bring people together in an open forum to discuss mental health issues, share experiences, and discuss whether the 'Bamford Vision' is being realised.

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

In contrast, many people expressed their **frustration at the slow pace of change** and the **long way yet to go**. A lack of resources and the impact of potential financial cut backs raised concern that the 'Bamford Vision' might be undermined.

Access to mental health services continues to be an issue. The further development of support in the community, particularly in light of the reduction of hospital-based services is considered important. Accessing services during a crisis was still thought to be difficult and there are barriers created in relation to the 'criteria' set around accessing such services. It was generally believed that there is a greater focus on the prescribing of medication rather than alternatives and access to therapies was considered difficult.

The important role of carers was acknowledged throughout the conference as was the need to support, listen to and involve carers in the planning and provision of services.

Another recurrent issue was the vital role of voluntary organisations and community groups in 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 the availability of services and local community resources.

Education and awareness raising about mental illness and mental health was seen as an important step in reducing stigma and discrimination and 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"*.

The outcomes of the triologue sessions and discussion workshops at the Open Dialogue Mental Health Conference provide an insight into how mental health

services are changing, and highlight key issues and work that needs 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.

Further details on the Open Dialogue Mental Health Conference and the findings of the '**Is Bamford Making a Difference?**' report can be accessed through the following link <http://www.patientclientcouncil.hscni.net>

4.4 Online Mental Health Information for Young People

The purpose of the project entitled 'Online mental health information for young people' is to allow young people to voice their views about the information on mental health services for young people available on the Health and Social Care Trust websites. It was also to determine if young people were able to access this information independently.

In total, **20** young people in **two** groups took part in a 'mystery shopper' exercise evaluating the five Health and Social Care Trust websites.

Young people identified a number of positive aspects of the information provided. One group found the 'CAMHS IN BRIEF' leaflet extremely useful. Others singled out the facility to enlarge text as a helpful feature.

The findings from this exercise show that **few young people were able to find any relevant information about mental health for young people on any of the Health and Social Care Trust websites**. This was particularly the case the first time they tried.

Most of the young people who took part in this exercise said that they would **NOT** have continued trying to find information on Trust websites if there had not been someone there to help and guide them. It is recommended that the information on mental health services for young people on Health and Social Care websites must be:

- **easy to understand and relevant to young people;**
- **written using terms young people recognise;**
- **accessible within a few quick clicks;**
- **written BY and FOR young people.**

The Bamford Monitoring Group recommends that the following actions are taken to address the issues raised in this report:

- The Health and Social Care Board should develop regional information about mental health support and services available for children and young people in Northern Ireland. This should include:
 - general information about mental health and wellbeing; and
 - information about all of the help available, from primary care to specialist child and adolescent mental health services.
- Health and Social Care Trusts should take immediate action to improve the information about mental health services for children and young people on their websites, based on the findings of this report.
- Health and Social Care Trusts should involve children and young people, in the development of information about mental health services in their local area, including that for websites.
- Health and Social Care Trusts should develop information specifically for children and young people and separate information for parents.
- Health and Social Care Trusts should ensure that all information on their websites for young people, including information about mental health services is easy to read, understandable and accessible for all people using them.

The 'Mental Health Information for Young People on the web' report can be accessed through the following link <http://www.patientclientcouncil.hscni.net>

4.5 Further Education

The purpose of the further education priority monitoring project has been to give people with a learning disability the opportunity to voice their opinion on Further

Education. A total of **88** people with a learning disability took part in this project at five further educational colleges across. Through these discussions a number of themes have emerged.

Most people enjoy being a student and feel that they have gained a lot from being at college. They like learning new things, developing a greater sense of independence, working towards a goal and the feeling of achievement that comes from gaining qualifications.

Many people said that they would like **more choice at college**. Some feel that there is a **limited range of courses** available to people with a learning disability. This resulted in some people repeating courses due to limited choice. Others mentioned that they had little say in what course they attend, since this decision is made for them by family members or advisors from school.

Nonetheless, attending college is clearly a valuable experience for many people with a learning disability and a significant step towards greater independence. It is important that college courses are good preparation for the future, aimed at progression into the workplace.

The Bamford Monitoring Group recommends that the following actions are taken to address the issues raised in this report:

- The Department of Health Social Services and Public Safety should liaise with the Department for Employment and Learning to ensure that further education for people with disabilities is protected and enhanced in line with service user needs;
- The Department of Health Social Services and Public Safety should liaise with the Department for Employment and Learning to ensure there is a clear and connected pathway for people with a learning disability to support their progression from school to college and on to the workplace. This planning should be person centred;

- Further education colleges should involve people with a learning disability in making decisions about courses and subjects available;
- Further education colleges should establish an ongoing way to hear what people with a learning disability think about college and courses available.

Further details on the further education priority monitoring project and its findings are in '**Further Education**' report. This can be accessed through the following

<http://www.patientclientcouncil.hscni.net>

4.6 Shaping Information, Knowledge and Access to Mental health Services

In October 2010, the Bamford Monitoring Group and Western Health and Social Care Trust jointly hosted a workshop 'Shaping Information, Knowledge and Access to Mental health Services' as an event to mark World Mental Health Day 2010.

The aim of the workshop was to provide an opportunity for people who use mental health services, and carers to shape, develop and improve access to mental health services in the Western Health and Social Care Trust area. Some of the opinions expressed during group discussions include:

- The importance of the GP as the first point of contact, and the need for GPs to be properly trained and aware of support services available to people with mental health needs;
- The need for a single point of access for information and advice;
- The need to have the right information, at the right time;
- The importance of involving people and carers in the development of information and advice about accessing mental health services.

Further details about the 'Shaping Information, Knowledge and Access to Mental health Services' event can be accessed through the following link

<http://www.patientclientcouncil.hscni.net>

5.0 Other Initiatives

During monthly meetings, the Bamford Monitoring Group takes action in relation to a number of important issues affecting mental health and learning disability.

Draft budget responses

In order to represent the interest of people with mental health needs, learning disabilities, parents, carers, family members and communities, the Bamford Monitoring Group sent written responses to the draft budgets of eight Government Departments. They included, the Office of the First Minister and Deputy First Minister (OFMDFM), Department of Health, Social Services and Public Safety (DHSSPS), Department of Education (DE), Department for Employment and Learning (DEL), Department for Social Development (DSD), Department of Justice (DoJ), Department for Regional Development (DRD) and the Department of Culture, Arts and Leisure (DCAL).

The Bamford Monitoring Group strongly recommended that Ministers and the Northern Ireland Executive as a whole, ring fence current funding and provide sufficient additional funding to enable the recommendations contained in the Bamford Review of Mental Health and Learning Disability to be implemented within the agreed timeframe.

Involving people and regional groups

One of the main duties of the Bamford Monitoring Group is to represent the interests of the public by engaging with the Health and Social Care Taskforce for Mental Health and Learning Disability and other relevant groups. Therefore, members of the Bamford Monitoring Group contribute their expertise to several important groups:

- Interdepartmental Official's Group;
- Health and Social Care Mental Health and Learning Disability Taskforce Steering Group;

- Mental Capacity and Mental Health Legislation Reform Reference Group and Steering Group;
- Regional Resettlement Steering Group;
- Regional Psychological Therapies Strategy Steering Group;
- Regional Card Before You Leave Steering Group;
- Regional Respite Steering Groups (adults and children);
- Regional Child and Adolescent Mental Health Services Subgroup;
- Regional Learning Disability Subgroup; and
- Regional Adult Mental Health Subgroup.

Continued efforts are being made to ensure that service users and carers are present and represented on the Health and Social Care Taskforce Mental Health and Learning Disability Steering Group.

Consultation responses

The Bamford Monitoring Group has responded to several relevant regional consultations, seeking to report the views expressed by people with mental health needs, learning disabilities, parents, carers and communities. These included:

- The Northern Ireland Dementia Strategy;
- The Mental Capacity (Health, Welfare and Finance) Bill Equality Impact Assessment (EQIA) Consultation;
- The Mental Health Nursing Framework; and
- The Service Framework for Mental Health and Wellbeing.

The group is actively involved with the Northern Ireland Service Framework group in helping to draft the Learning Disability Nursing Framework.

Research

The Bamford Monitoring Group assisted the Health and Social Care Research and Development Division of the Public Health Agency to prioritise research topics relating to the Bamford review of Mental Health and Learning Disability.

Members of the Bamford Monitoring Group were actively involved in the scrutiny of research proposals relating to the Bamford Research priorities.

Our report entitled 'The Mental and Emotional Health of 16 year olds in Northern Ireland' (Patient and Client Council, 2010) has this year been endorsed as a recommended resource by the Education and Library Boards and the findings presented at a number of international conferences.

Key issues:

The Bamford Monitoring Group addressed several other issues throughout the past year. These included responding to:

- The evaluation of 'Delivering the Bamford Vision' (DHSSPS 2009) and associated Action Plans;
- Regional respite review undertaken by the Health and Social Care Board;
- Uptake of Direct Payments;
- Psychological Therapies and Cognitive Behavioural Therapy;
- Independent Living Fund;
- Impact of the Treacey Judgement;
- Electroconvulsive Therapy (ECT) usage;

A list of presentations made to the group in the past year can be found in Appendix 4.

6.0 Ongoing work

Several monitoring projects are ongoing and brief details of these are given below.

6.1 Resettlement from learning disability hospitals

Currently, the Bamford Monitoring Group project team are meeting people with a learning disability in both the Belfast and Southern Health and Social Care Trust areas. These individuals have previously lived in a learning disability hospital and now have a home in the community (resettlement). The purpose of this work is to:

- Find out what people with a learning disability (and parents, carers and family members) think about where they live in the community and how this compares with living in hospital.
- Understand how people with a learning disability, parents, carers and family members were communicated with and involved in the process of moving from hospital to living in the community.
- Explore how people with a learning disability, parents, carers and family members believe the process of moving from hospital to living in the community could be improved.

The Bamford Monitoring Group project team are in the process of one to one meetings with people with a learning disability. Outcomes from the work will be reported in March 2012.

6.2 7 day follow up after hospital

The purpose of this project is to design and implement a method to obtain and understand the views and experiences of people who have been discharged from mental health inpatient services, regarding the continuing care and support provided after discharge.

This project has taken time to develop and progress. A steering group of mental health service users, carers, and representatives from voluntary organisations and community groups has been established and several meetings held to date.

Bamford Monitoring Group members are working in partnership with mental health service users and carers on all aspects of the planning, design and delivery of this project. Support is being provided from colleagues in the Bamford Centre for Mental Health and Wellbeing at the University of Ulster.

A project planning day was held on 21st July 2011 and a detailed proposal was drawn up to support the project. This requires ethical approval prior to field work commencing. Outcomes from the work will be reported in March 2012.

6.3 Card Before You Leave scheme

The Bamford Vision Action Plan states that 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 – this is known as the ‘Card Before You Leave’ Scheme.

The Bamford Monitoring Group is undertaking a project aimed at gaining an understanding of the experience of people who have been through the ‘Card Before You Leave’ Scheme; what it was like in A&E, what the follow up appointment with mental health services was like, and if they believe the help offered by the scheme was beneficial.

Initially, this project commenced as a pilot in the Northern and Southern Health and Social Care Trust areas. A significant amount of work was undertaken with Health and Social Care Trusts to prepare and communicate with patients and invite their participation. Furthermore, to guide the discussion with participants a series of prompts and topics were developed with the input from service users and carers.

Difficulties with the process of identifying participants and the operation of the ‘Card Before You Leave’ Scheme arose in the Northern Trust area. This led to the decision

to broaden the evaluation project to all Health and Social Care Trust areas in Northern Ireland. Individual one to one interviews are now underway and a detailed report of findings will be produced in December 2012.

6.4 'Beating the Blues'

The Bamford Vision Action Plan recommended that the computerised Cognitive Behavioural Therapy (CBT) programme 'Beating the Blues' should be introduced in Northern Ireland.

The Bamford Monitoring Group designed an online survey to capture the views and experiences of people who have used 'Beating the Blues'. Initially, four GP surgeries in Northern Ireland were approached inviting their patients to participate in the survey. The survey has also been made publically available through the Patient and Client Council website. In addition, notification of this work has been circulated through the Patient and Client Council membership scheme.

Correspondence regarding the survey has been sent to all GP surgeries in Northern Ireland and made available on the Health and Social Care Primary Care Intranet sites. Further, a letter has been circulated from the Chair of the Northern Ireland General Practitioner Committee of the British Medical Association endorsing this work and encouraging GPs to inform their patients of the survey.

Outcomes from the work will be reported in March 2012.

7.0 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).

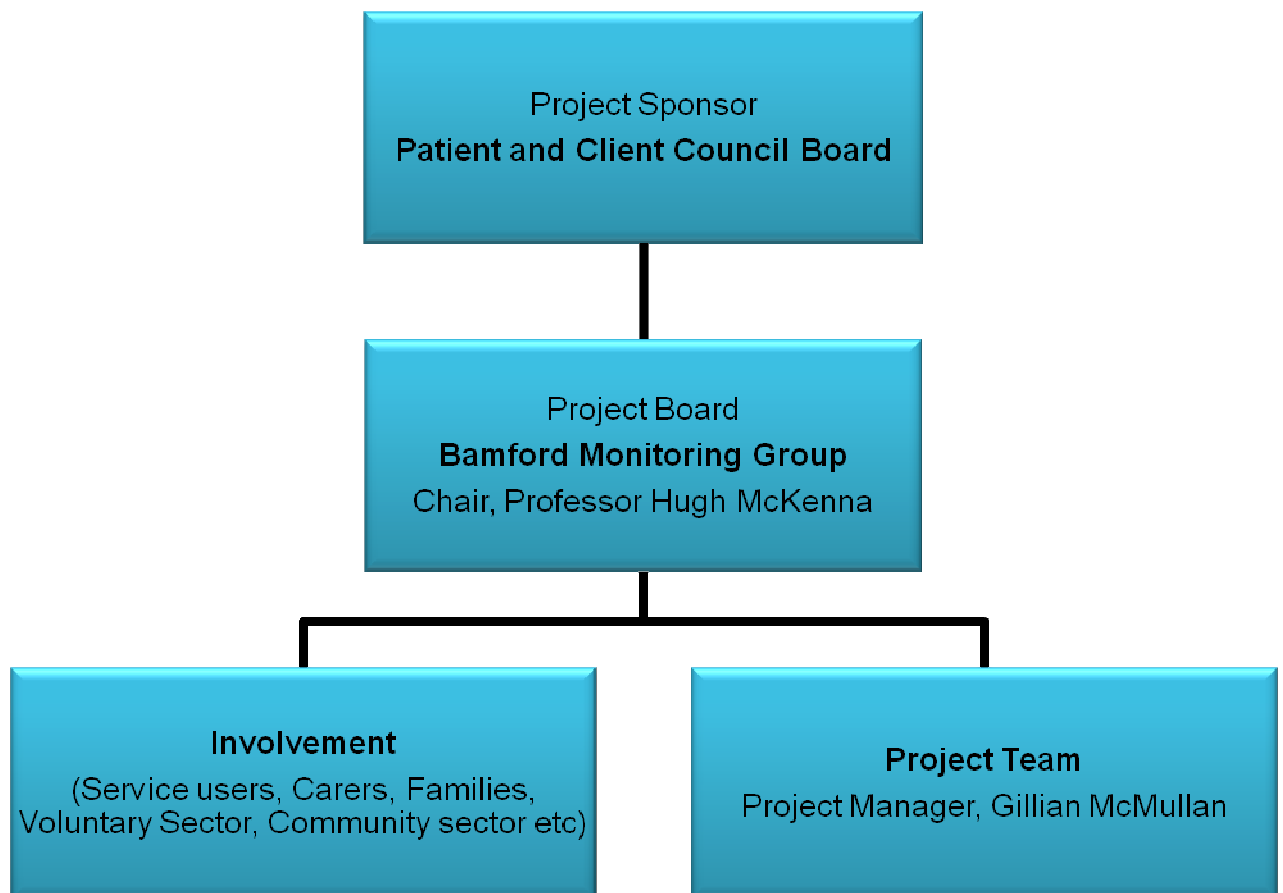
Patient and Client Council (2010) **The Mental and Emotional Health of 16 year olds in Northern Ireland.** Belfast: Patient and Client Council (June 2010).

Appendix 1 – Bamford Monitoring Group Members

Hugh McKenna	Chair, Bamford Monitoring Group
May McCann	Vice Chair, Bamford Monitoring Group
Marie Crossin	Carer
Mary Duffin	Carer, member from July 2011
Joseph Richard Ewing	Service User, member from July 2011
Sandra Harris	Carer
Lisa Jane Henry	Service User
Maeve Hully	Chief Executive, Patient and Client Council
Elaine Kelly	Patient and Client Council Board Member
Martha McClelland	Service User
Joanne McDonald	Service User
Patricia McDowell	Carer, member from July 2011
Paul McFall	Service User, member from July 2011
Catherine McGroggan	Service User, member from July 2011
Gillian McMullan	Project Manager, Bamford Monitoring Group
Brian Sinnamon	Carer
Louise Skelly	Head of Operations, Patient and Client Council
Marion Smith	Patient and Client Council Board Member
Janice Smyth	Member until June 2011
In Attendance:	
Paschal McKeown	Client Support, Mencap
Seamus Logan	Health and Social Care Board
Aidan Murray	Health and Social Care Board

Appendix 2 – Bamford Monitoring Group Project Structure

The Bamford monitoring project structure is as follows:



Appendix 3 – Patient and Client Council Membership Scheme

The Bamford Monitoring Group uses various means of reaching and communicating with people. The Patient and Client Council membership scheme is a key mechanism in this regard.

As of 31st July 2011, there were a total of **2,612 members** of the Patient and Client Council Membership scheme.

Total Members	2,612
Individuals	2,266
Organisations	346

Of the total 2,612 member, many people have shown an interest in expressing their views on, or experiences of, mental health and learning disability:

	Mental Health	Learning Disability	Both MH & LD
Individuals	253	177	1,151
Organisations	51	28	197
Total	304	205	1,348

The membership continues to expand and we hope that people will join and get involved.

Appendix 4 – Presentations made to BMG

The Bamford Monitoring Group has been delighted to welcome several people from within the mental health and learning disability community to formally present to the group and keep us informed of their work.

A summary of those who have met and presented to the group are as follows:

Presentation	Attendee
Bamford Research Priorities	Gail Johnston, Health and Social Care (HSC) Research and Development Division of the Public Health Agency.
Perinatal Mental Health research	Shona Hamilton, Queens University Belfast
Regional Advocacy Framework	Alison McCaffrey, Department of Health and Social Services and Public Safety

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