

The Way I See It

**Personal Views on User Involvement,
Partnership Working, Inclusion and Real Life**

Compiled by Brendan McKeever

Disclaimer: All the articles in this book are the personal views of the individuals concerned and have been commissioned freely. Although many of the contributions have far-reaching implications for all those interested in this subject, they are still the personal opinions of those writing and have been offered in good faith to create discussion, debate and action.

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Preface

“I believe the key component to honest and effective involvement in all aspects of services lie in the relationship we have or can develop with each other: in effect, we need to understand better the ‘realities’ of each of our situations as well as the perceptions.

“It is this recognition of the individual, family and community’s strengths and resilience which can be a powerful force for change and one which highlights true involvement and inclusion, even in the most challenging situations.”

Martin McCafferty

In the pages that follow, there will be many opportunities to look at different realities, to see in practice the relationships, or lack of them, between people from different perspectives. We hope that this information and knowledge will help to move the debate on user involvement, inclusion, participation, partnership working and real life out of the theories and into the reality of those who plan, deliver and use services. In real partnership, this can happen. These articles may help in this.

We are grateful to all those who have become involved in this project, particularly those who have written the articles and given so freely of their time. It is very much appreciated. Thanks also are due to Joe and Paul of Guildhall Press for all their help and advice. This book reflects real-life situations and experiences. Another publication, *User Involvement – More Than Words*, is also available on the website:

www.familyinformationgroup.org

This gives the background and references to general user-involvement issues.

Introduction

'User involvement' has become the buzz phrase in recent years. Research, reports, guidelines, focus groups and government policy have all tried to explore what this means. Despite this, some users will claim they are not involved at all. Some of those who actually deliver services will claim that they do not have enough time or the energy to really involve people, there is so much pressure at work. Certain service planners have struggled for years to develop guidelines in how to involve users.

On the positive side, there are good examples of user involvement in both the voluntary and statutory sectors. Furthermore, there has been extremely inclusive research highlighting key issues in relation to user involvement. Currently, there is more awareness in the statutory sector that user involvement is becoming a necessity rather than a luxury.

However, user involvement means different things to different people, and it is valued differently. Seldom are staff working on the ground consulted on this or any other issue. User involvement cannot work without them.

Sometimes the views of individual users take second place to those coming from groups. User involvement cannot work without these individuals.

At times it appears that those who could have the most critical input as to whether user involvement will be effective are overlooked.

Only when there is a fuller understanding of user involvement, an appreciation of the barriers preventing it happening, the identification of things that work and actually seeing this in practice, only then can the real challenge of putting words into action happen.

In reality, if we believe user involvement can help create more efficient services, as it is claimed, then by addressing the barriers, by learning from good practice and from being more informed, we may see more people willing to get involved and more opportunities at inclusiveness.

In this book you have a unique opportunity to learn from others who have such diverse opinions and experiences in life. Whether it is called user involvement, inclusion, participation, partnership working, or simply real life, it does not matter.

Each contributor, in their own way, has risen to the challenge and in turn challenged us to think differently and to reassess our own values. If user involvement requires a culture change, the seeds to that change are contained in these articles.

It was a demanding task (see Appendix 1 for Guidelines) to ask people to give of their time freely, just before and after Christmas 2007, and to produce accessible articles from their own perspective on this issue. The result is a collection of individual thoughts and perspectives which blend together to answer almost every question that could be asked about user involvement, and to do this in a plain, clear and accessible way.

For users, there is the acknowledgement of their value, the need for them to be engaged, to be respected, and the same is true of those who work directly with them and who are often ignored or overlooked. For organisations, there are explicit suggestions and ideas of how to get involved. Those who are seeking core values, underlying meanings and the essence of user involvement, they will definitely find them in the pages that follow.

Why put this together and who is it for?

It is for you the reader, whoever you may be – student, user, Social Worker, staff member, community worker, in the field of health, Social Care, housing, education, recreation or whatever. It is aimed to help you understand what all this is about, no matter what spin is put on it, and to broaden your way of looking at life.

At a personal level I have worked with virtually all the contributors, in some way or other over the years. I have grown to respect them and their work, even if I do not always agree with their opinions. We have learned to work in real partnership, valuing each other and learning to go on this journey together. This book is testimony to that partnership working, which gradually, slowly has started to make a difference. Thanks to all of them.

Brendan McKeever

29 February 2008

Not the Words – What They Mean

User involvement is similar to a one-to-one relationship. Sometimes relationships can be difficult, but often underneath, a relationship is quite simple. Just as is user involvement.

Relationships are based on **trust** and **values**, and **respecting** that trust and those values, and being sensitive to these.

For a relationship to grow, there needs to be good **communication** between people so that they can understand each other and realise where each person is coming from.

There has to be **knowledge** of each other; how else can people engage? This is real knowledge, not perceptions, not second-hand, but getting to know each other.

Many people will argue that their experience is more than enough for them, that they do not need any additional help. But there are those who recognise that they need additional skills sometimes. Mutual **training**, training that will help them both engage more fully, will help them acquire skills that they just do not have. This training often needs to be led by those who have

direct experience in a particular issue, rather than a formal professional training package.

The mechanism that keeps the relationship running smoothly is often found around everyday practical issues, support and, of course, **resources**. All the values, principles and respect in the world are not enough unless you have the proper resources and ensure all the **practicalities** are sorted out.

Relationships will often fade if there is no **feedback** between people, no real **outcomes**. It is obvious that when people see no purpose in a relationship, feel used and their only value is for someone else's purpose, often someone who does not seem to value them, then this can be the end. Feedback and outcomes are critical.

Finally, **networks** are important for any relationship; usually these are made up of like-minded friends and acquaintances. As a rule, these networks are not set up for a specific purpose – to suit other people, for example – they are chosen freely, and those involved decide who and why they get involved with others.

About The Contributions

The contributions should be read in full if you wish to gain a fuller picture of what user involvement is all about. The different views and challenges will help you in understanding what at times is a very complex issue, but which at other times is simply common sense.

There will be some who naturally just want a short recipe of what they need to do, a checklist of requirements needed to fulfil user-involvement requirements. The requirements are certainly in these articles, but they will not find the recipe or checklist. User involvement is much more than recipes and checklists.

From parents of disabled children to those working in the community – both in statutory and voluntary services, as well as those who have their own specialist interests – these are the contributors who so willingly agreed to take part in this project. What started out as an idea to gather about ten papers on this subject to be used for talks and lectures has mushroomed.

All the significant values and principles associated with user involvement are here in these articles. But what is significantly different

here is that the contributors have made these values and principles real; it is not examples from life, it is life itself. As highlighted in a number of articles, user involvement is a journey, a process; it is ever changing. For many, it is real.

Different views, different perceptions, but all valuing user involvement, all respecting each other, all striving to explain what this means. These articles challenge all our ideas about user involvement; they make us go deeper into our understanding to emerge with a rich knowledge of what it takes and an openness to at least try.

Many of those who have contributed will never have had any previous work published; some may never have written in this way before. Their contributions and their sharing have been offered to help us understand. A recipe does not necessarily make a good cake; a checklist is not necessarily the implementation of something. These contributions, however, not only give you the most nourishing cake, with the fullest checklist inside, but much more. Read on!

The Contributors

Anne Cullen sets the scene as a user, as the parent of a disabled child, in her description of what life is like for her. It is direct, honest and it is this real-life experience which is the basis of user involvement. This is just not a 'story', told for the sake of telling, it is a reflection on a journey, a reflection that should help all of us focus on key issues that are part of user involvement.

Colin Devine, in a different sense, is just as direct and challenging as he explains how user involvement relates to the community. The importance of valuing users as well as staff, of shared information and knowledge, and of developing networks is also emphasised.

Joe Duffy brings all his academic expertise and his deep commitment to inclusive practice to this article as he relates it to his work in Social Work studies at Queen's University. Joe is the author of two pieces of research into user involvement and is part of a team at Queen's that works constantly to engage users at different levels of university life.

Maria Fox tackles the complex issue of being doubly marginalised: first as a Lone Parent

and then with an added area of marginalisation as featured in a Gingerbread NI research report. This research is based on true-to-life experiences and raises many questions that remain unanswered.

Anne-Marie Gallagher relates user involvement to marketing forces and in a very direct way looks at the local picture in Creggan Country Park while broadening this out to general issues and looking at customers as users. She vividly describes the efforts made in the Park to engage their customers and to positively respond to them whenever possible.

Jeremy Harbison takes us on a journey, a life journey with the Northern Ireland Social Care Council as it attempts at times to live up to its user-involvement ethos. It is honest, direct and very clearly shows a body really trying to come to grips with this, acknowledging its limitations and its willingness to move forward. It is a soul-searching exercise.

Frances Heywood goes back into her wealthy history of community involvement to draw out a real example of practical involvement in Birmingham. A snapshot in time of a very innovative approach to how some people made

genuine efforts to engage a local community and what this meant.

Paul Hipsley takes user involvement into a different realm as he looks at community publishing at Guildhall Press. Despite the change in scenery, Paul vividly describes the same principles of listening and involvement as there are in other areas of user involvement and highlights their unique approach to publishing.

Alison Jarvis of one of the leading social research organisations – Joseph Rowntree Foundation. In this piece, Alison is contributing as an individual and challenges our thinking of definitions and gives a very relevant example of how partnership working is the basis of any user-involvement practice. She emphasises that everyone should be valued and respected and that one group cannot work alone.

Eddie Kerr challenges our thinking and attitudes in this article, encouraging us to move away from pre-conceived ideas and perceptions. Also, he puts user involvement into the wider picture of community development and raises the question of its relationship with funding. Partnership working is seen as critical to developing user involvement in this piece.

Hilary Maguire of the NI Children's Hospice. In her article, she explains in depth the Children's Hospice development of user involvement over the years. She illustrates the issues that have arisen for them, the barriers they have faced and how they have tried to overcome these in very practical ways. It is an honest and comprehensive analysis which is challenging and engaging.

Maura Mason gives a practical example of how the Childcare Partnership made efforts to develop user-involvement practice. The piece shows how the Partnership learned lessons, reflected on its own efforts and how theories and practice emerged which have helped the Partnership to develop its work in this particular area.

Martin McCafferty, from his everyday work in Creggan Day Centre, has put together an article that goes beyond all the hype and jargon. In realistic terms, he strips away all the trimmings, and user involvement is exposed as real life, real lives lived. It is a challenging and disturbing article that forces us to see people as they are.

Kate McDaid illustrates a practical example of how authorities at Altnagelvin Hospital tried to work in specific areas of user-involvement principles. Again, it emphasises the necessity to

listen to users and to act on what they say. It is a practical example of how users and staff come together to make changes.

Conal McFeely puts user involvement in the context of his Social Development work in the Ráth Mór Centre in Creggan with his customers and those tenants of the Centre who provide services. The work ethos, focused and centred on the community, is drawn from that community. These are not buzz words or concepts, but action which through hard work and commitment has seen user-involvement principles translated into real jobs and businesses.

Brendan McKeever tries to leave aside all the trimmings of user involvement and return to what he hopes is a user perspective of one of the most significant changes to policy influenced by partnership working and user involvement: the Homes Fit For Children Campaign. He returns to the basics of this campaign and attempts to retrace the steps that moved what seemed a very individual issue into the political arena of change.

Siobhan McKeever has a different view on user involvement. To Siobhan and the group of parents she knows, it is about trying to do something which will make a difference. It is

about having the experience to know what is best. It is also about being willing to work with others. If all this adds up to user involvement, then Siobhan and her friends are interested. In her article, it is clear that user involvement is about action, about doing something, not about theories. Her group has made a difference simply because it is user based.

Tina McLaughlin shows in her article how people can be thrust into the role as users with no warning or preparation. In a very honest account, this article reflects some of the core values of user involvement, but in very practical terms: the importance of respect, of involvement, of acknowledging expertise and of listening to users – all basic requirements, requirements that sometimes can be ignored as Tina so vividly outlines.

Christy O'Donnell draws on the community he lives in to give examples of user involvement where carers were directly involved. His examples are a very good illustration of how carers, working with others, can meet real needs in very positive ways: in supporting families as families and in providing necessary information in quite different ways. The examples given by Christy show the difference user (carer) involvement can make.

Mary O'Neill brings her own personal experience as a parent of a disabled young person to her description of how she found her voice. Moving from that very personal experience as a mother, she describes her journey into a support group and then on into an action group, successfully bringing change by working with others. User involvement is very important to Mary and she clearly knows what it takes to make this work.

Gillian Presho takes us directly back to the users: young disabled people. Within a Cedar Foundation project, she illustrates the importance of involving young people, in developing their skills and tells how Cedar, through this project, actively engages the young people themselves.

Walter Rader and Joanne McDowell vividly explain the core values which inform the application process for relevant lottery grants. This is not a quick guide to grant applications; it is an attempt to look beyond the process to the importance of really engaging people as a basis of working, and engaging them at all levels. A number of examples of good practice are given.

Keavy Sharkey interestingly utilises her skills in communication to show in very clear language the importance of open and honest

communication. She stresses the importance of really listening and of actually hearing what is being said, this is not always the case in practice. Keavy has interpreted so well one of the core values and skills in user involvement, then relates this to the real world.

Trisha Ward, writing in a personal capacity, summarises the various ways that the Library Service has tried to engage users in different ways, at different times. The difficulty of engaging users is acknowledged, but practical examples are given of honest attempts at inclusion. It is a challenging article that offers a lot to think about.

The Articles

Try, Try, Try Again!

Anne Cullen
Parent

None of us are perfect; all the theories on user involvement will not make it work. What really makes it work is living it.

As the parent of a twelve-year-old boy who happens to have cerebral palsy and as the mother of a nine-year-old girl, nowadays I feel well-qualified to write about user involvement. I am a parent/carer. For over a decade, I have had to be the voice of my boy; otherwise he would have had no voice. I have had to struggle with bureaucracy, which at times, to put it mildly, has not been helpful.

Years ago, I admit I did get angry. As a user, I was frustrated with negative attitudes, insensitivity, lack of understanding, disrespect and ignorance. Even recently, when my son was transferring from primary school, I was shocked at the attitude of someone I expected more from, someone in authority, when my son was dismissed because of his disability, from even being considered for a particular school.

Attitude, if you ask me, is one of the most fundamental things that need to change if user involvement is to work. People, perhaps through training, perhaps through awareness, need to know what it is like to be a user and/or carer. Of course, without living our lives, they cannot fully know, but perhaps understanding can be a good starting point.

With attitude, respect is another real issue. Often it has been when my son or I have not been respected that I become very angry and emotional, even though I know being emotional is not always helpful when you want to challenge others. But life is real for me; it is not part of an academic theory, and sometimes emotions do come to the fore. If it was your child, would you not feel the same?

Prejudice and discrimination are real; we cannot hide away from these, and if user involvement is to work, then we have to work at ridding ourselves of them. It is work, hard work, but I can assure you it is not as hard as ensuring that your children have a reasonable quality of life that is more of a challenge.

By now, you probably think: how could I ever get involved with others? How could I

overcome all the negative stuff in life? As I said, it is hard work, but I believe if you work at it, good things can happen. I also have to admit that most of those professionals involved in our lives have been sensitive, caring, respectful and trustworthy, and many really did engage with us.

It may have taken time and building up of trust, but make no mistake, in our own little way, user involvement was and is working. Several years ago when I began to feel that I deserved respect as of right – because of my experience in life – then I was more confident in dealing with others, particularly professionals. This respect, positive attitude, hard work, living in the real world, all contributed to a more positive way of working: user involvement in action.

What I am saying is very simple: do not let user involvement become the next *in-thing*, like partnership working, empowerment, capacity building or, God forbid, the subject of a university degree. If that happens, we will have lost what it is all about.

It is about my son, my daughter, and our lives. It is about how we treat others and how they treat us. It is about mutual respect, it is about hard

work. There is room for everyone, particularly those whose life experiences have educated them far more than books ever could.

Sometimes we forget we are human, that we can make mistakes. Professionals can make mistakes too. We are all learning – if we could just appreciate this.

I do not often look back now. Why should I recall a time when not only had I to deal with the pain of diagnosis, but also the unhealthy, insensitive attitudes that some people had? And when I felt useless so many times? That was then, this is now.

We did not get here by accident; user involvement is not something you lift off the shelf. But do not be fooled, this big picture of user-involvement issues is only the wee small user involvements of individual lives. It is the daily caring, the negotiations with professionals; it is living. Never forget this: it is the living out of our lives and how this crosses with others.

I now know that my son, my daughter, my family and myself have the right to a decent quality of life. We have a right to be heard, a right to be respected. It is our present and our future. And

if user involvement means that we all should be directly involved in sorting this out, then I am all for it; isn't it what we do anyway?

I remember standing alone in front of a crowd. It was at a conference and I was nervous, worried, concerned that I would not be able to say what I wanted to. As a parent, I never feel comfortable talking in public. But I spoke, and spoke from my heart, and as I spoke, I gained even more confidence. In the room were many professionals, some even with university degrees and professional qualifications.

But that day, I knew I was more qualified than many of them. My qualification was life, and when I spoke about partnerships, I knew what I was talking about. Partnerships (the theme of the conference) and user involvement are the way forward; just look at what has not worked.

But what if we fail? I might hear you say. I already have said we all make mistakes. If we try, try and try again, how could we fail? We are in this together – there is no failure. I will not fail my son or daughter, be assured of that.

Big Difference

Colin Devine

North West Community Network

“There is a big difference between feeding into someone else’s ideas . . . and developing your own.”
(*Making User Involvement Work*, Joseph Rowntree Foundation, 2006)

North West Community Network is a long-standing community-development organisation that arose from a recognition by grassroots community organisations of all types and sizes that there was a need for a focal point for representation, a conduit through which advocacy and influence could be channelled and maximised.

Many different definitions of community development are in circulation, but it is surely true that they each have at their core the guiding principles of equality, inclusion and participation. Even a cursory examination of each of these makes clear that user involvement is a key ingredient within the community-development mix.

The tenet that every man, woman and child has the inherent right to be involved in the decisions that impact upon their quality of life, is there

much room to question this? It may be, for some, naïve to adopt the position that this is the only approach to service design and delivery that makes any kind of sense. But it is hard to escape the wisdom of a recently heard comment: “If you want to know how well a pair of shoes fit, you ask the person wearing them, not the person who made them.”

User involvement has achieved a higher profile over the last decade or so, but as often as not, when and where it occurs, it deals with aspects such as user satisfaction in response to services already received. This is far from the sum total of what user involvement is about – it needs to be a cyclical, cradle-to-grave practice, from needs identification to service design, service delivery and, of course, review. Like community development itself, user involvement is not simply something you do, it is the reflection of a culture of inclusion, it is about how, and not just which, services are designed and delivered.

For user involvement to become a default element rather than a discreet observance to legislative duty, there is much that community and voluntary groups can do. Fundamentally, we need to ensure that the deep reservoir of knowledge and experience that exists within our

own service users is given due value, that it is drawn out as a key element in our own service delivery.

Groups must build such feedback into their practice – not just to participate in the currently uneven and inconsistent user-involvement practice – they must have the confidence to speak out when they feel that these fall short, let public bodies know not just that their methods and style are unsatisfactory, but guide them towards what would work better.

What is also crucial in the quest for effective user involvement is the awareness that there is strength to be gained from sharing – across areas, across organisations, across age groups and across any other platform that allows mutual support. For individuals and groups to have belief that their own experiences are important, it is imperative that linkages are made with others – from this, confidence, eloquence and conviction will grow.

Networks, formal or otherwise, are needed to validate and capture the experience at the level where it really matters. Public services embody the responsibility the state has towards its constituents; it makes perfect sense for people

like you and me to have the opportunity to facilitate this responsibility being met.

Community and voluntary groups also need to place a high value on how well-placed they are to make genuine user involvement more of a reality. If policy can be influenced by experiential and knowledge-based evidence, as we are told it can and should, the proximity of community groups to those who have this experience and knowledge is second to none.

It is not just that community groups have access to service users, it is also that they tend to work to a certain set of values and principles (often unnamed), a culture of ethical service delivery that quite naturally gives rise to advocacy on the basis that they know of what they speak.

There is also an education process that community groups can help drive forward – that user involvement is not just about consultation, or at least the consultation practice that we have become used to: staid, impenetrable, single-format circulations from public bodies that allow little time for meaningful response (and no investment to support it), or tokenistic public exercises that can amount to little more than a head count and a box checked off on the to-do list.

There is no such thing as consultation fatigue – what many are worn down by is being consulted badly! As a sector that exists in part to reach where statutory provision struggles to impact, we have developed skills around flexibility, innovation and variety of approach. Much good practice is already out there, including within public bodies, and where it exists it needs to be highlighted and built upon.

There are ‘champions’ of user involvement in many places – these need to be supported and encouraged. There are community-development functions within many large statutory bodies, albeit often on the fringes; these are resources that can be used to advance the understanding of what real user involvement looks like. This latter point is self-contradictory – user involvement is not about just one approach; it begins with according the respect due to service users and working out how to show this comes afterwards.

In the Northern Ireland of today, individuals and the communities they come from have an opportunity to grasp. We have a political and social landscape that seems to want to make things better for everyone; we have outward signals that placing more influence within reach of the average citizen is to be delivered through the Review of

Public Administration (RPA) (and in Health and Social Care, ongoing work on Personal and Public Involvement - PPI), and we have a community and voluntary sector that is well-placed to ensure that the promise becomes real.

That is not to say that challenges do not exist: with a restored Assembly and ever-evolving structures in health such as Local Commissioning Groups, communities have much learning to undertake to understand how the system works.

The mechanisms exist to allow greater influence to be exerted, but the capacity to make use of these is not yet where it needs to be. Through participation, working with an equality focus and ensuring that inclusion is possible for all, including the hardest to reach, user involvement can be brought in from the sidelines to become a fertiliser for effective public-service design, delivery and evaluation.

We do not just need better user involvement; we have a right to it.

User Involvement in Social Work Education – A Way of Working

Joe Duffy

Lecturer in Social Work, Queen's University, Belfast

This short piece will examine the meaning of user involvement in the context of Social Work education. Firstly, however, it is important to look behind some of the meanings behind these two words before looking more closely at what these represent in Social Work education.

What we do know about user involvement is that it has a distinct but relatively young history. In terms of Social Work, it was first represented in the early seventies as 'client studies' in the early work of Mayer and Timms (1970). The notion of *service user* is now widely used in Social Work literature and replaces other terms previously in common usage such as client, customer, consumer, etc.

More recently, yet more terms are emerging such as Patient/Personal and Public Involvement, Citizen, Expert by Experience, etc. It would seem that none of these terms can claim to have total popularity, as weaknesses can be found in all of them – a debate for another day!

This short piece, however, will focus broadly on *user involvement* as meaning that we, the public, may have experiences of receiving health and social-care services in the past or may have at some point in the future experience and influence of such services. It also refers to carers as users of services as they interact with service providers on behalf of/in the interests of family members they are caring for. For me, therefore, user involvement represents the interests of a lot of people!

The Degree in Social Work, introduced to Northern Ireland in 2004, marked the beginning of user involvement taking on a central and important role in the education of Social Work students. User involvement is now present in all aspects of this education in terms of how it is delivered and managed by the two universities and their partner further-education colleges in Northern Ireland.

What does this look like?

Currently what happens is that service users and carers (Citizen Trainers) share their experiences with Social Work students in different teaching modules. They do this through small group discussions and giving talks in the universities and more recently through inviting small groups of Social Work students to visit specific groups/ facilities in the community.

Is this making a difference to the quality of Social Work practice?

The simple answer is we don't know as yet, but this is something we need to more closely examine – and something I will be conducting further research into in the next year. What we can confidently say, however, is that the user-involvement experience is highly valued by Social Work students. One student commented recently after a service-user lecture that this experience reminded her why she went in to Social Work in the first place!

Nobody doubts the value that Social Work students need to get from literature, theory and research, but I consistently hear students commenting that “we can't get this from books” in their reactions to user contributions in their teaching. It is interesting to note, however, that books are now emerging which do have accounts of user perspectives, so students may no longer be able to confidently make such a claim about the quality of what they read!

Are we there yet?

I think we are making good progress and I am pleased that good-practice guidelines we published last year (Duffy, 2006) are being taken on board by students and Social Work educators.

The place we need to more firmly move to, however, is where user involvement is naturally thought about in everything we do in relation to Social Work education. Users don't need to be, and I'm sure wouldn't want to be, involved in every meeting, committee etc to do with the Social Work degree. But what is important is that we all think firstly: is this something where we should be asking our user colleagues to contribute?

This is what 'a way of thinking and a way of working' looks like in terms of user involvement and this is not complicated. What this does, however, is *mainstream* user involvement in a way where it becomes a natural way of thinking for everybody in relation to all aspects of Social Work education.

How are we going to get there?

In the short time I have been working and doing research in the area of user involvement, I have found a real commitment among user groups to being involved in Social Work education and among academic colleagues in supporting this. I am, however, aware that not everybody wants to be involved in initiatives like this, so it is very important that users are supported in this process.

Continuing to look at different, challenging and innovative ways to involve user perspectives in Social Work education will hopefully build the capacity of Social Work students and users alike. What will be the ultimate guidance for us all, however, in terms of *getting there* will be the need to avoid taking for granted things like the importance of the Values and Principles associated with this work, the importance of Practicalities, Communication and Feedback. These are not complicated ingredients, but in the busyness of our working worlds, there is always the danger that these can get lost in translation!

I have to avoid the temptation of getting into *writing guidance* on this, but the points just made are at the centre of this *way of working* in terms of user involvement in Social Work education and beyond, and the most important point to remember in all of this is that *this is not complicated*.

User Involvement – Not Alone

Maria Fox

Gingerbread Northern Ireland

Who are users?

Users are clients, parents, carers, service users, citizens, customers, consumers, patients etc.

What is user involvement?

User involvement is the uptake and usage of services; user involvement should also involve users being involved with the planning and any change of service.

What are user-involvement issues?

There are many issues: some users don't use services as much as they would like to because of how they will be perceived. For instance, young lone parents are sometimes less reluctant to visit their health visitor, as they feel they may be perceived as not being able to cope. Male lone parents are also at times reluctant to use family services, as they perceive them to be geared towards women.

User involvement is very important for all service providers, as users should be at the core when planning and delivering services.

Confidence is an issue in user involvement, and people who are lacking in confidence and self-esteem may also have difficulty.

Good communication is key, but service providers need to be aware of the circumstances of their users and be understanding. Sometimes there can be the perception that users' views and needs will not be valued and again, users are sometimes less than confident in coming forward.

This can prevent user involvement working properly. In the instance of lone parents, it can sometimes be perceived that there is a stigma attached to being a lone parent and that they will be judged more harshly than others, therefore preventing them from being users.

However, despite the reservations just highlighted, user involvement should lead to positive change if it is planned and developed effectively. Users need to feel valued, and if they are, then positive change should be achievable.

One very practical example from our own work is a report we produced some months ago. *Not Alone* was research that Gingerbread Northern Ireland carried out to highlight and raise awareness of what we would call our users.

This publication gave voice to real user involvement: lone parents who also faced additional challenges in their lives, telling their stories, as they saw them; bringing these voices together, working with other agencies and supporting our lone parents if they needed support. This was a practical example of how user involvement can work. It takes time, effort and commitment, but it is very rewarding and can help towards positive change.

Gingerbread Northern Ireland is committed to this.

User Involvement – Marketing in the Public Sector

Anne-Marie Gallagher
Creggan Country Park

Creggan Country Park is a community business based in an area of high social deprivation. We offer outdoor activities, training and employment and meeting space to the local and wider community. A major part of our service is facilitating community-group projects using outdoor pursuits as a vehicle for project progression.

We would define user involvement as the process where users of our services take an integral role in service design. That is, our customers inform the design and evolution of our products and services. It involves capturing collective experiences and feeding key practical recommendations unfiltered into service design/delivery.

We do this by using focus groups, surveys, online questionnaires, on-street research and generally working very closely with customers. Different users prefer to offer feedback in different ways. For example, 80% of our customers are aged between eight and fourteen years. This age group

will not respond to a questionnaire, but they will use the comments section on our website and take part in focus-group-style research (as long as it doesn't take very long!).

The issues surrounding user involvement are wide and varied. The physical process of feeding users' contributions into service design is fraught with difficulties. It is relatively simple to listen to customers, but more difficult to accurately record and action their recommendations. Sometimes those recommendations can challenge the very essence of service provision and it can take courage to act on the information provided.

There will be occasions when practical limitations make it impossible to deliver/act on key issues identified by customers, but we have found that the more involved our customers become in our organisation the more they understand those limitations and why certain decisions are made. Indeed, an understanding of difficulties faced by service providers has produced innovative answers from customers to long-standing questions. By working together on mutually agreed limitations, we have found that the power of providers and users together is a much stronger force for change than either group alone.

Our organisation is small and information can proceed from customers to service providers very quickly with little 'noise' during the communication process. However, larger organisations face difficulties in that there can be sometimes a much longer line of communication between users and those who are tasked with designing/delivering services. This can mean that information gathered can be diluted or misinterpreted before reaching its destination. This is a major barrier to effectively involving users.

Creggan Country Park would refer to users as customers: that is, all those who interact with the services we provide. We do not sub-categorise customers. From our point of view, an important principle of user involvement is that each interaction is equal and no contribution invalid. This should be the foundation when attempting to encourage user involvement.

Organisations seeking to explore user involvement should first get straight within their own structures why exactly they are bothering. Would it not be easier to just plug away with what you know and fire fight problems as they occur? There's no doubt that would make life easier, but in the long term, this approach, a bit like a

rolling stone, collects cumulative problems which will lead to major problems for the organisation. Left untreated, these cumulative problems will eventually paralyse the organisation. The reason we should all be bothered is not to be nice, but to survive.

User involvement is crucial; its value lies in quality and progression of service provision. Service provision is not static; it should be in a state of perpetual motion – continuously evolving and moving forward. Users provide the fuel for this continuous movement. Their involvement should feed the process and make it better by continually testing and changing provision.

This involvement works best when the basic principles of user involvement are genuinely accepted throughout an organisation. Paying lip-service to the value of user involvement will not benefit the organisation. It must be accepted that all contributions are valid and equal and that the main beneficiary of user involvement is actually the service provider.

It's important that it is easy for users to get involved and that they believe their contribution will count. Without this, user involvement is meaningless.

There is undoubtedly a risk that the principle of user involvement can become yet another buzz word for use in an annual report never to be seen or heard of again. Some users struggle to keep up with the latest 'customer-service initiative' on offer and can become jaded.

This is a major barrier to user involvement working. As service providers, we need to prove that we can be trusted to act on customer's ideas and aspirations. It's important to actively 'sell' the idea on to customers; they must become part of the organisation.

The important thing is for the organisation to genuinely commit to the principle, have the right people listening, the right mechanism in place to collect information and the willingness to act on that information. Clear lines of communication which can collect and distribute information equally well are also necessary.

Changing aspects of service provision can be done with little effort and no input from users. Creating *positive* change is an entirely different matter. In my view, that can only be achieved by giving equal credence to the views of those who receive a service and those who provide a service. Change should not be for change sake,

but because there is an anomaly that needs to be fixed.

Creggan Country Park sees customers very much as a resource in the same way as our staff, equipment, fixtures and fittings. As an organisation, we changed the way we looked at customers in 2004 and began to listen to what service they wanted, when they wanted it why they wanted it and how they wanted to hear about it. Then we acted on it.

We have been able to increase visitor numbers (watersports only) by 443% to 13,412 in 2007, create 17 jobs, and 98% of customers tell us they are “extremely happy” with their experience here. In a two-year period, we developed three new products which funded two jobs by listening to our customers. Those are the reasons that user involvement is important.

Coming from a marketing background, user involvement is really just marketing described in a different way:

“Identifying and anticipating the needs and wants of your customers and delivering on them profitably.”

Chartered Institute of Marketing

Private-sector organisations spend thousands of pounds on this holistic process. They do this because they know that the yield on this spend (or return on investment) is extremely positive. If they fail to keep up with their customers, a competitor will and the business goes nowhere.

This applies to anyone providing a service. Whereas some providers have a monopoly on service provision, if their customers are not getting what they need and want from the service, that frustration will vent itself in one way or another and the organisation will eventually lose.

Fire-fighting gaps in provision as they occur is not the answer; private-sector organisations have recognised this for decades. In summary, I think that all organisations become more efficient and flexible if user involvement is ongoing. They have much to learn from commercial providers and the principles they apply to this process.

User Involvement in the Northern Ireland Social Care Council

Jeremy Harbison

Chair, Northern Ireland Social Care Council

In this brief article, I want to consider our experience in the NI Social Care Council (NISCC) of user involvement. My definition of ‘users’ covers people of all ages who receive Social Care and Social Work services, as well as those who are heavily involved in Social Care as carers.

I will briefly describe what the NISCC is, then describe the importance of user engagement with the work of Council. I will outline how we have taken forward our efforts to make sure that users’ influence is fundamental to our work, consider some of the areas where I think we have been successful, some issues or difficulties that we have met, and then I will look forward to the next phase in our work to further strengthen user input.

The Northern Ireland Social Care Council was established by the Assembly on 1 October 2001. Its major objective is to protect the public, specifically those who use Social Care services, and to promote confidence and competence by users in the Social Care workforce.

We work to achieve these goals by registering and regulating all Social Care workers and Social Workers, by setting and monitoring the standards for professional Social Work training by the NI universities and by promoting training for the whole Social Care workforce.

From the start, the involvement of users was established as fundamental to the work of NISCC. Background papers by the DHSSPS, discussion in the Assembly and the supporting documents prepared following the passing of the necessary legislation all emphasised the central role that user involvement must take in the new public body.

The Department took an important policy decision that when members were appointed to the governing council of NISCC, one third should be able to reflect user and carer experiences. A further third of members were to be Social Care and Social Work registrants, and the final group of members was to come from employers, universities or other 'stakeholders'.

But very importantly, each member was appointed as an individual on the basis of what he or she could bring to the work of the Council – to set the right policies and strategy for NISCC, to make

sure the staff delivered these priorities, and to ensure the proper use of public funds. A review of the Council by the Department in 2005 confirmed the central principle that users should continue to make up a third of the governing board.

So, users have been an integral part of the governing structure of NISCC from the start. The first committees set up by Council were carer and user reference groups, and these continue to the present. All committees and working groups of Council include users as core members.

So, how successful have we been, and what impact has the involvement of users had? We are on a journey in this area. It has been a difficult and at times challenging journey, and one that is far from over. I personally have found my views challenged and changed during this process. I think, on quite a lot of fronts, we have been successful, and in a range of key areas, user involvement has been a very important driver of our work.

The governing structures at every level involve users as described above. User input has been hugely important in the development of our Codes of Practice for Social Care workers and Social Workers. The new university degree in

Northern Ireland has user engagement written in as a requirement for those universities delivering the courses.

Users are part of the panels who consider complaints against registrant Social Workers and Social Care workers – which can lead to individuals being struck off the NISCC register and not being able to continue working in Social Care. The annual plan that sets out the work programme and priorities for NISCC has user input from the start of planning.

Most importantly, however, I believe we have developed a user ethos across every aspect of Council's work. As an example of this, during debates on issues at the board of Council, it has been, increasingly, members from registrant and stakeholder backgrounds who have argued for or challenged whether user impact or involvement was good enough.

But Council members and staff know that we still have quite a distance to go in our efforts to maximise user involvement in our work. Some areas where more work is needed include how we can combine making business papers within Council accessible to all members while meeting the requirements of being a public body.

We know we need to greatly improve knowledge among users about the role and responsibilities of NISCC. We must work more effectively to build user input to our business planning. We must evaluate the success of our work to date, for example, through the introduction of the new Social Work courses – do students emerging from these courses really appreciate the necessity of user involvement in every stage of their professional work?

And critical to many of these issues is how we can best engage with users. The reference groups we established at the start of Council have been very important and have made significant contributions to our work across various areas. But we are increasingly asking whether there is a better way of getting the width, range and depth of input we need for our work from users. Our own reference groups can never include the full range of users, from widely differing ages, with very different requirements of services, across the whole of Northern Ireland, who receive Social Care.

With this in mind, we, along with two other organisations committed to developing user input into their work (the Regulation and Quality Improvement Authority and the Social Care

Institute for Excellence), have commissioned an important piece of research to help guide us on the next stages of our journey. That work is now completed, will be considered at our next Council meeting before being launched in February 2008. I am sure that this will help our new Council of NISCC, appointed in October by the Minister and again including one third of members with user experience and expertise, to develop still more the potential of user involvement in every aspect of the work of the NISCC.

Our journey is far from over, and an important lesson that I have learned is that we will never reach an end point on this journey. To deliver really strong and effective user involvement requires ongoing challenge, review and change in our work. The journey must continue because the end – better, more responsive and sensitive Social Care – requires continuing and recurring effort.

Birmingham Community Forum

Frances Heywood

Researcher, Bristol University

This is a story of user involvement in Birmingham that was sustained for over thirty years. It is a story that many of those involved feel ought to be told, so I welcome the chance to give at least a brief account.

It began amid the bulldozers of the 1960s, when in many of Britain's cities, vast areas of 'slums' were cleared and the people moved out. But as it became clear that the tower-block estates that replaced the terraced housing were, for many people, a disaster, there was a backlash. And it was a combination of public protest and economic necessity after the oil crisis of the early 1970s that led to plans in many cities to replace the wholesale clearance of old houses with programmes of renovation, and to consult the people concerned about how to do it.

One of the first cities to go for this in a big way was Birmingham (never a city to do anything by halves), and although many other cities followed the path of renovating the houses, we in Community Forum never found a system of

consultation and involvement equivalent to what was set up in Birmingham.

It began not with stropky residents, as I should like to claim, but with one or two councillors and with officers who had a vision of a new kind of Urban Renewal, which included some of them moving into poor areas and getting to know the people for whom they were planning.

This experience of the realities of inner city areas was to prove very sustaining as they later rose in their careers: it is like the old model of University Settlements which introduced Attlee and other founders of the Welfare state to realities they never forgot.

When we talk of participation and involvement, it is often about citizens being invited to give their views on an officer-set agenda, but this process of officers going and getting their hands dirty alongside the relevant people in the people's own territory is a model that has much to commend it. Better than a dozen courses!

The structural model which they then set up was of Urban Renewal teams, each one located right in the neighbourhood it was to serve and made up of architects, planners, environmental health

and housing officers and a team leader with a large budget and considerable autonomy.

Their brief was to begin the process of renewing streets and mainly privately owned homes, and consultation and involvement of local people was key to their thinking. But they didn't try to keep control of this. In each area, they worked to set up independent residents' groups who would then become the residents' voice.

So the professionals leafleted and called public meetings, and invited those who came along to form a residents' group. Once these were underway, they sustained them by paying for meeting rooms and helping with leaflets, but they did not interfere in any other way.

What they did do, as plans for renewal of walls, roofs, windows etc were rolled out and people were tempted with grants to take part in the schemes, was attend countless meetings and make themselves available to be questioned, criticised and shouted at. They kept coming back, though, and gradually (though you might not have realised it from the nature of the exchanges), a respect and understanding grew between them and the highly suspicious citizens.

They became familiar figures in the streets around the offices and soon 'Urban Renewal' was part of the community. This was real, sustained, month-in, month-out consultation, where officers were available to be held to account; and it went on for years.

Such was the foundation of the individual residents' groups, but over these was something even more remarkable: Birmingham Community Forum, an umbrella group of residents' groups. And having praised the officers for how they set up the consultation structures, it is time to praise the remarkable volunteer citizens who ran Community Forum for the next thirty years.

The officers were unpaid, but the organisation received financial support for many years from a Birmingham charity, the Barrow Cadbury Fund, which enabled them to employ a worker to carry out their wishes. This funding, given with minimal fuss and paper work and with much faith, enabled Community Forum to remain independent of the council and so free to criticise or research fearlessly. This is part of the model which contrasts so strongly with the bureaucratic nightmares of European funding, for example, and which made the consultation so good. I wonder if the Cadbury charities have ever spent money better . . .

So, what did the Community Forum do? The answer is, it brought the representatives of the individual local groups together, listened to their problems and campaigned on issues that affected them all.

When in favour, it met regularly with the councillor who chaired the Urban Renewal Committee and with the Department's senior officers; when out of favour, it met anyway and found other ways of being heard. And just as local people had come to value the Urban Renewal officers, so the officers realised the value of a group that could speak out on issues where they agreed but were not free to comment.

The group campaigned on the subject of cowboy builders, leading to a completely different approach from the city; it suggested the technique that became the national policy of 'enveloping' and then fought for changes in how this was done; it suggested 'Patch and Mend' grants, which, again, became national policy.

And it campaigned continually on behalf of people who still had to face the trauma of losing their home to compulsory purchase. After a research project in which the City Council and Community Forum combined, it was agreed that

long-term, ongoing consultation was needed for residents of clearance areas.

Officers of all the relevant departments took part in the monthly meeting, and Community Forum sent representatives who went out and visited the areas concerned to bring back direct feedback of problems. In recent years, this was done alone by Community Forum's voluntary secretary, Pat Priestman.

Pat epitomised everything about this model of consultation. She was independent, feisty and critical, but also, because of the long years of involvement, very knowledgeable and understanding of the officers' position.

When she died suddenly and tragically in 2007, there was at her funeral a remarkable tribute: a wreath from the officers Pat had so often called to account. And on it was written:

“To the living memory of Pat Priestman with grateful thanks from the City Council and people of Birmingham. Pat was tireless in her help for residents who faced the loss of their homes. Her work will continue into the future. She will always be greatly respected, warmly remembered and sadly missed.”

I end the article with this salute, because it sums up, better than anything else I can think of, what was achieved by a system of consultation that was based on adequately resourced independence for the 'service users' and given time to grow into mutual respect and interdependence between officers and people.

In Memory of Pat Priestman

User Involvement in Community Publishing

Paul Hipsley
Guildhall Press

Guildhall Press has developed an expertise in designing and publishing high-quality books, promotional material and websites over a number of years. It caters for specialist interest groups, the commercial sector and individual creative writers.

However, although the finished product is important to Guildhall Press, the process of reaching this final product is just as important. As a community publisher, the roots of the not-for-profit organisation are founded in the community and community-development principles.

What we call users may be very different from how they are defined in Health and Social Care circles, but nonetheless, our customers who use our services, as well as the end users (the readers), are our lifeblood. They could only be ignored at our peril. Indeed, if we had not developed a user-centred ethos, we could not have attracted the wide range of business that we have. In fact, user involvement has not only kept us in business, it has actually developed our work.

It may seem a cliché, but it is people before profit. We value our users, we respect them and are first to acknowledge their expertise. We then match their particular expertise with our own. In partnership, we then work to deliver a high-quality product. We bring the design and publishing skills; often, they bring the information and specialist knowledge.

Core to our understanding of user involvement is the ability to listen, genuinely listen, and then to act on what we hear, so there are agreed outcomes. This takes time and the building of confidence and trust. Frequently, this can be a very challenging process. Most of our users want to be a priority, want the publication yesterday, and at first may not be interested in any of our outstanding work.

But to us, true user involvement is about mutual respect. We respect the user and we expect the user to respect us. With users that avail of our services regularly, this mutual respect often develops over time. Then there is more pre-planning, more time to discuss key issues, more time to actually give the user what they want, but on realistic terms.

In relation to the Family Information Group, we have nurtured a strong and positive base from

which to work which is totally user focused. This does not mean that it was always easy, but it has always been fruitful and rewarding. But our service to them is the same service we offer everyone, and years of work with the Group have created a real wealth of experience on both sides.

At first, their user ethos and priority on accessible information did challenge us. Established formats for publications did not always suit and much time was invested not simply in proofreading around grammar and spelling, but indeed more important to the Group, the removal of jargon and the monitoring of language to ensure it met with Plain English standards.

This proofreading went even further as we examined and read publications as 'neutral observers', just to see if we could understand the issues. The benchmark was if we, with a background that had no knowledge of them, could understand these issues, then we would expect parents, families and those who work with them to fully understand them. For us, this has been a very important task and reflects our respect for this particular user element, which is seldom important to others, but part of the core values of the Family Information Group.

An additional service we provide is ensuring the actual design, layout and presentation of all material results in information that is legible, logical and easily navigated. To us, communication of the message has primary importance, not how it looks. You see a lot of examples of leaflets, brochures, publications, websites etc where the designers get carried away with the many possibilities that are available through modern technology. This can result in a visually 'cutting edge' piece of work which may look good, but where the font size is too small or where unrelated graphics obscure the text, or the text is too 'blocky' with no sub-headings to guide the reader.

The challenge here is to attempt to combine the core text with attractive graphics that contribute to the readers' understanding of the message rather than impress or distract them with superfluous design features. Again, the relationship we have developed over the years with the Group makes this task easier, as they accept our advice on not 'over-designing' the various material produced.

We acknowledge that it is very important that the Group do address their core value of ensuring those who use services are involved in the

planning and provision of services. Although we offer distribution services to all our users, the Family Information Group insist on launching their own publications and on distributing these through their networks. This has worked very well for the Group and we have assisted wherever possible; at other times, we have willingly taken a back seat.

For our users also, we source relevant information from our networks, which they may not be able to access. We also offer real value for money, as we constantly monitor the pricing structures of our existing suppliers, or seek new ones, to make sure that users are being given the best deal at any particular time.

Guildhall Press were tested thoroughly when the Family Information Group became involved in a housing campaign (Homes Fit For Children) to abolish the means test on parents of disabled children. The campaign itself has subsequently become a model of good practice for user involvement and effective partnership working. At the time, we were tasked to translate what at first was a very complicated and specialist area – housing grants for the disabled – into accessible and understandable information formats, often against very tight time scales. At

the same time, we had to remain sensitive to the Group's wishes and to the issues affecting families. It was a learning process in which we willingly engaged.

Within a period of time, we had published three separate titles and four brochures, all on the housing issue and at a minimum cost to the Group. It has been acknowledged that our support was invaluable in winning this campaign, which has significantly enhanced quality of life for many disabled children. Although those outside the immediate area or fields that the Family Information Group work in know little about this campaign, the final publication, *Making the Impossible Possible*, is used by a wide range of people who have a general interest in user involvement issues.

More recently, Guildhall Press was commissioned to create a website for the Family Information Group, with financial support from Derry City Council. It holds all the Group's publications, which can be downloaded free, and soon there will be two new titles added to the ever-growing web publication resource. Although now complete, it will be continually evaluated and updated to ensure it meets with the changing needs of the organisation.

In 2007, the website became a focal point and 'rallying tool' to secure funding for the Group. Its real-time updating facility provided an accessible platform for users to express their support for the Group and register evidence of its impact on the various communities. This meant that potential funders could quickly and conveniently be presented with all the up-to-date facts on the Group's work and be made graphically aware of the weight of public support within the wider community.

For many, user involvement is a concept, a theory. But for Guildhall Press, it is a practical reality. We have chosen to make this a priority, because it reflects our own ethos and because it adds meaning to what we do. It is cost effective and it also makes common sense. Sharing expertise and having an agreed focus – fundamental to user involvement and critical in our work with the Family Information Group and others – is the only way forward. We have still much to learn, but there are many teachers, particularly those who use our services, from whom we can learn.

User involvement – A Personal Tale

Alison Jarvis

Joseph Rowntree Foundation

Let's get the wording out of the way first. Like most people (everyone?), I am a user of public services. But personally, I prefer to call myself a person. So that's the last you'll hear of the term 'user' in this article.

I should like to share a story that, for me, sums up the point of involving the people most affected by an issue in taking it forward.

I am a research manager by trade. I work for a charitable outfit called the Joseph Rowntree Foundation, which funds a lot of research about lots of different Social Policy areas. We don't do the research ourselves; mostly it is done by academics. My role is to look over their shoulders and make sure they're keeping on the right track and also, importantly, to make sure that the end result is not left on a shelf to gather dust but is used to influence the thinking of those who need to be influenced, and to achieve change where change is needed.

One of the ways the Joseph Rowntree Foundation tries to do this is by setting up

Advisory Groups around the projects it funds. We try to make sure that all the different groups of people with an interest in the issue being researched are represented on these groups.

Over the years, I have looked after a number of projects about the lives of people with learning difficulties, and particularly about their housing circumstances. One of the early projects I looked after was carried out by a great researcher (and a great man, sadly now deceased) who was absolutely committed to involving people with direct experience of learning difficulties in his work.

The Advisory Group for this project involved a number of people from a self-advocacy group; these people brought a lot of value to the process and helped to ground the project in reality. Perhaps even more importantly, though, they challenged us with the question: Why aren't we actually *doing* this research; why are we only commenting on it? This evident dissatisfaction – with one of the most committed researchers I had/have ever met – was both frustrating and exciting.

The years passed and another opportunity came along for researchers to bid for funds to look at the lives of disabled people in communities. Who should apply but the same self-advocacy group

who had made life in the Advisory Group so difficult! And not only did they apply, they also got the money to go ahead.

The team have recently completed their study and, as luck would have it, their publication coincided with the results of another piece of work dealing with similar issues that had been carried out by an academic institution. They are very different studies, with very different approaches, and very different styles. But lots of the messages are the same. We have therefore been able to promote both of the studies together, and both have been strengthened by the presence of the other.

So what is the point of this story?

Well, first, don't underestimate the impact that people can have by being a pain. Only by making your voice heard can your voice be listened to. Secondly, don't be afraid to chance your arm and take a risk. If you assume failure, you may well get it. If you assume success, you might just strike lucky. And thirdly, from the Joseph Rowntree Foundation's point of view, don't be put off having your cake and eating it too. Had we produced a single report by people with learning difficulties, we would have reached some people

and influenced some people. Had we produced a single report from an academic institution, we would have reached and influenced others. But with reports from both, we have the potential to be bigger and bolder in our plans.

So the final point is this: in any task you do, involve the people whose input matters to achieve what you want to achieve. And it is very unlikely that if the task concerns a policy or service, the people who are subject to the policy or are using the service will not be part of the equation. Not profound, but worth remembering nonetheless.

Links to summaries of the studies mentioned can be found at:

<http://www.jrf.org.uk/knowledge/findings/socialcare/610.asp>

<http://www.jrf.org.uk/knowledge/findings/socialcare/2124.asp>

<http://www.jrf.org.uk/knowledge/findings/socialcare/2106.asp>

What Makes Us Stronger Makes Us More Efficient . . .

Eddie Kerr
SEEDS

As a society, we must be committed to producing programmes and structures which involve families and young people at the pinnacle of the service. The family is paramount, we are often told, and as each child and family are unique, the services on offer must reflect this uniqueness.

So, in order to facilitate effectiveness and efficiency, we must target resources and policies to support families and the young people involved. That means that we must involve people, including young people, and their families and carers in decisions that affect them directly and with that purpose clearly in mind.

If necessary, we must change the way we work with people who use services by including them in the decision-making process and planning stage as much as the monitoring and evaluation processes. This means we must find ways of working together better; working together in ways that respect the life experiences, life expectations, knowledge and expertise that

users and carers have to contribute. Valuing people puts service users and carers central to the development and delivery of services stating. This applies to decisions on day-to-day matters such as choice of activities; operational matters, such as staff selection; and strategic matters such as changes to eligibility criteria.

It is no longer acceptable for organisations to view people with disabilities as passive recipients of services; they must instead be seen as active partners. Many service-user organisations and individual service users often feel isolated. Inadequate and insecure resources, low profile and the need to compete with big charitable organisations and each other are major problems.

One wonders sometimes how high up the agenda this group is. I acknowledge the problems with reduced budgets and spending priorities, but for what is a little investment, a lot of community-led projects, like the Family Information Group, can achieve the near impossible. Imagine what could happen with serious investment in these groups?

Sometimes service users may feel that their knowledge is generally not valued or taken

seriously by professionals, policy-makers and services. The closed culture of Health and Social Care services and their own inadequate resources restrict service users' capacity to develop and share their knowledge.

Social Care services have so much to learn from families and carers that it is almost negligent to ignore their contribution to the process of learning and sharing. Maybe we are looking at a future partnership where service users can offer user-led training and education to service workers and professionals.

Maybe we want to stop using terms like 'dependent' and 'independent' and use 'interdependent' where partnership is key. This is a two-way process. Maybe we are looking towards a time when there will be a commitment to change and evolution in services which will instil a process of sharing and caring as real partners. Maybe the inclusion of diverse service-user perspectives will offer more support for service-user networking.

This, to me, is the key to strengthening service-user knowledge and enabling it to have greater impact on provision and eventually ingrained in policy. I acknowledge we came a long way, but

this is not a destination: it is a journey that takes services onwards and upwards.

So, in my view, making links and connections will make the service stronger and more efficient and ultimately will achieve more for those who can benefit most – families and young people. Isn't that what it is really all about?

User Involvement – The Children’s Hospice Experience

Hilary Maguire

Clinical Services Manager, NI Children’s Hospice

Why?

User involvement is a key consideration to the Children’s Hospice for several reasons:

- It informs and assists the appropriate development of a new service
- It improves quality by highlighting areas of service which require improvement
- It prioritises areas of improvement
- Major funders usually require that applicants demonstrate high levels of user involvement.

How?

At the Children’s Hospice, user involvement is considered to be an important element of our service. Users of our services include children/young people, their siblings, parents and professionals who refer families to our service.

A Needs Assessment of children/young people with life-limiting conditions was published by the Children’s Hospice in 2000 (Maguire, 2000). This took into account four areas: available services,

professional opinions, prevalence study and opinions of children/young people and their parents.

Children's Hospice Community services were developed in response to the Assessment of Need and the actual Hospice facility (Horizon House) opened in autumn 2001. Initially, parents were represented on the Steering Group, which informed the development of the service, but this Steering Group no longer meets and the user involvement is lost.

Presently, user involvement in Horizon House involves satisfaction surveys of parents, use of the Association of Children's Hospices' (ACH) Quality Assurance Tool, with children/young people and their siblings and the user (children/young people and siblings) focus groups to determine service development and needs. Recognition must be given to the need for an organisation such as the Children's Hospice to use innovative and flexible communication methods to facilitate participation and representation from all users – for example, music therapy or art.

Hospice at Home – Services in the Community have been funded in some areas by the Big Lottery Fund. In these areas, Steering Groups have been formed to manage and develop

these services locally. Key members of these groups are parents; one group has a young-person representative.

Annual user-satisfaction surveys are carried out to inform service quality and improvement, and two pieces of qualitative research have been completed looking at User Evaluation of the Hospice at Home Service and the Respite Needs of Adolescents/young people (both awaiting publication).

Room for improvement

There is a growing realisation among the Children's Hospice Service that we need to further develop user participation and partnerships, especially in areas of service delivery, service developments, quality, improvement and prioritisation of improvements. We are presently investigating models of user (parent/child/young people) groups with representation from all areas of Northern Ireland. Identified obstacles we are seeking help from ACH with are:

- How do we invite representation?
- How do we ensure equitable representation?
- How often should we meet?
- Where should we meet (considering some families live ninety miles from Horizon House)?

Getting it right for service and users

As a voluntary organisation, the Children's Hospice often delivers services in partnership with other agencies. I personally consider that true partnerships should include user representation. One partnership that I have been involved with is the Western Children's Hospice At Home Service, where participation of the user representatives was considered equally if not more important than any other stakeholder.

However, lessons learned from this have been the need to ensure users are made to feel confident and given the support to participate in such steering groups and partnerships. Recently, an external evaluation of the partnership was carried out using the 'Model of Partnerships for Health' framework proposed by the Institute for Public Health in Ireland (2001). The model is designed to be used in a number of ways, including for established partnerships in the assessment of the effectiveness of their operation.

The 'Partnerships for Health' model has a number of key elements, namely:

- The **grounding** – that the partnership is built upon a diversity of people, groups and organisations who share a desire to work in relationship with each other

- The **core foundation** – the shared purpose and hoped-for benefits of collaborative efforts
- The **outcomes** – what is achieved, planned and unplanned, by working in collaboration
- The **process** and **contextual** factors – which affect the everyday activities of the collaboration.

Contextual factors, or factors external to the partnership, influence the work of the partnership by presenting opportunities and constraints.

The model also recognises that the partnership process and these contextual factors influence each other on an ongoing basis. The partnership may be able to influence contextual factors, but it will almost certainly not have full control over them. Contextual factors are different for every partnership but may include:

- Previous connectedness between individuals, groups and organisations – history of working together
- Political climate – the history and environment surrounding power and decision making, with a healthy partnership recognising the political climate as a resource and so setting out to engage a diversity of support for the shared vision of the partnership

- Policies, laws, regulations – partnerships are more likely to succeed when supportive policies, laws and regulations are in place, especially within the collaborating member groups and organisations
- Resources – within a partnership, resources can be in the form of environmental, in-kind, financial or human capital.
- While environmental (contextual), in-kind and financial capital are important, the model stresses that human capital is the most important asset in a partnership.
- Catalysts or drivers – to get the partnership started. The problem or situation that the partnership comes together to address needs to be recognised by partners as one which requires a comprehensive response. The second type of catalyst required is a convenor – one who draws partners or potential partners together for discussion on possible responses to the original issue. Convenors need to be respected and seen as a ‘legitimate player’ if the partnership is to move forward and establish a shared vision.

All elements of the Partnerships for Health framework are **grounded** in valuing and respecting diversity – honouring the validity of the unique contribution,

role and position which each person, group and organisation brings to the partnership. Grounding happens when the members of the group are able to understand the perspectives of others on current reality, even if different, and each other's ideas about courses of action. Differences of opinion are viewed as healthy and predictable and are used constructively to increase understanding and produce a meaningful, well-thought-through vision and purpose:

“Valuing difference is the *raison d'être* of multi-sectoral partnership and must be recognised as a strength and core principle. Partners' strengths should be identified and utilised, and time needs to be taken to learn about each other and promote understanding, as this will go some way to promoting trust.”

The **core foundation** represents the common ground for the partnership – a shared purpose and strategy. Building the foundation includes the development of the following:

- Vision, or image of a desired future, and mission, or purpose of working together: the vision and mission describes why the partnership approach matters, because it defines the partnership, what it exists to achieve and how it fits into the wider world

- Principles, or guidelines for the way of working, and values, or beliefs the individuals in the partnership hold
- Measuring impact – how impact will be evaluated
- Infrastructure – setting out clearly how the day-to-day business will be carried out
- Contribution – making explicit what is expected from members and so encouraging commitment – why they are there, how they will be held accountable and the incentives they need to stay involved.

People may need to be facilitated to participate fully according to their support needs. It may be helpful to establish a formal partnership agreement with ground rules, principles of working together and the rights and responsibilities of members.

There also needs to be awareness raising in stakeholder organisations so that they understand their obligations and responsibilities to support their representatives and the partnership as it begins to build up momentum.

Process factors are internal and relate to the specific skills and dynamics of the partnership,

which are needed to build effective working relationships and capability.

It is important that members understand the dynamics created between contextual and process factors so that they are able to diagnose the reason why difficulties and problems arise as well as being able to spot opportunities which can be exploited in their interest. Process factors include:

- Leadership – chairperson (ensure the right people are in the partnership, establish structures, roles and responsibilities, develop mechanisms for decision making and conflict resolution, facilitate and support team building, capitalise on diversity and ensure political and cultural sensitivity, optimise group and individual strengths); members need to play an active role in all aspects of the work of the partnership
- Communication – partnership efforts depend on clear and open communication, within and beyond the partnership
- Team building – deepening understanding of each others experience and recognising the validity of each other's viewpoints. Through teamwork, the partnership is able to mobilise resources to overcome potential barriers and achieve change. A sense of trust is essential to successful collaboration

- Sustainability – systems are needed for sustained membership, resources and effort. Efforts must be ongoing to ensure that the appropriate level of time and resources are available to pursue the mission of the partnership. Planning must be short term and long term. The partnership needs to be able to identify emerging trends and issues and develop strategies for action
- Research and evaluation – obtaining and utilising information – evaluation efforts are essential to monitor progress related to the partnership’s goals and objectives and to make modifications as necessary. Strategies for communicating impact are also important.

Outcomes are usually, but not exclusively, defined following the development of a shared vision. Focusing on the desired outcomes in the initial stage of building a partnership is more likely to increase its effectiveness. This also promotes engagement and participation.

As a manager of community services at the Children’s Hospice, I believe that applying, if not the model, then the ethos of the Model of Partnership for Health (2001) to our user involvement and user partnerships will

strengthen the ability of our users to become effectively involved and achieve the best outcomes for our service.

User Involvement

Maura Mason

Co-ordinator, Western Childcare Partnership

I feel I should say that the following is my own experience of supporting the implementation of a User Involvement Strategy within the Western Childcare Partnership and may not represent the views of others also engaged in this piece of work.

Incorporating user involvement within the work of the Western Childcare Partnership has been a long process. However, it was felt that user involvement was essential in ensuring quality childcare services were being provided to children and their families as well as ensuring children's rights are being upheld.

Additionally, quite frequently, childcare services are the first outside-of-the-home services encountered by young children. Experienced childcare providers quickly recognise those children and families who may need additional help. If adequate supports can be secured, they can often prevent the child from falling behind during those early years, which research has demonstrated as being crucial to a child's longer-term positive development and wellbeing.

Engaging with very young children may appear to be problematic. However, the Childcare Partnership's experience has been that it is possible to consult with very young children, provided appropriately trained facilitators are on-hand to support the process. The Partnership researched a number of organisations that can either provide this type of training to childcare staff or can carry out research with children directly.

The Partnership also identified childcare providers and parents as prime service users and set out in 2005 to begin the process of actively seeking the opinions of these two stakeholder groups. A member of the Parent's Advice Centre (PAC) was engaged during 2005/2006 to consult with local parents' groups. Subsequent to this, PlayBoard and the Early Years Organisation (formerly NIPPA) undertook research to engage with childcare providers and children using their services.

The results of these initial pieces of work were interesting in that they revealed the groups of users were unfamiliar with the role and remit of the Childcare Partnership. However, the Partnership was keen to respond to the issues raised, as consultation is a two-way process.

The Partnership was quite clear on its role. It was established in April 2000 to:

- Assess the supply and demand for childcare and family-support services
- Raise the quality for childcare services
- Set achievable targets to fill identified gaps and direct investment to meet those targets
- Produce a Childcare Plan with a strategic focus on meeting the universal childcare needs of families and young children
- Ensure that reliable and accessible information on services is available to service providers, parents and the public at large.

As a first step in raising awareness of the role of the Childcare Partnership, a leaflet was designed and forwarded to all of the childcare providers within the Western Childcare Partnership Area for sharing with parents who used their services. The leaflet (available from the Childcare Partnership) was intended to provide parents with the necessary basic information they would need in meeting their childcare responsibilities and further signposting information should they decide to pursue a particular issue further.

Additionally, the leaflet indicated that the Partnership would be keen to hear directly from parents on their experiences and needs in relation to childcare. The Childcare Partnership's contact details were provided as well as the email address for the newly established parents' enquiry line: childcare-info@whssb.n-i.nhs.uk.

Copies of the leaflet were forwarded to all childcare providers in the Western Area to be distributed to parents using their services. They were also shared with the Western Education and Library Board Services for further dissemination.

With this initial task completed, the Partnership then began to consider how it could actively target sample groups of Users throughout the Partnership Area in a way that was meaningful to them. The Partnership considered the ideas on User Engagement as provided with the Western Health & Social Services Board's *Guide to Public Involvement and User Engagement*.

From this, the Partnership decided that it needed to engage a facilitator to support its plans for actively engaging with users of its services. The facilitator supported a working group to identify the areas where further feedback was needed

from the various stakeholders. The working group focused on three key areas: Health, Education, and Care. A questionnaire was devised and a preliminary plan was agreed to begin consulting with Users through several of the local Sure Start Projects.

At about the same time, a priority was placed on the Childcare Partnership to prioritise the expansion of the Sure Start Programme into twenty-seven additional ward areas within the Western Area. The sheer logistics involved in the Sure Start Expansion Programme meant that plans for progressing the work undertaken under user involvement had to be delayed. However, the Partnership made a point of keeping user involvement on its Action Plan for 2007/2008.

As efforts had been made to clarify the role of the Childcare Partnership among parents, it was felt that something needed to be done to raise the awareness of childcare workers as to the importance of engaging with users of their services. Clarity of purpose should assist childcare providers in developing their own policies on engaging with users.

It should also make it much easier to conduct local consultations through existing Sure Starts,

another target set by the Partnership to begin in early 2008 and follow through during 2008/09.

So, the next identified steps in the Childcare Partnership's plans for bringing forward its User Engagement Policy are to:

- Provide Training for Childcare Providers on the Importance of engaging with users of their services
- Conduct local, focused consultations within several Sure Start Areas (urban and rural, mixture of settings) as previously planned.

I hope the actions undertaken by the Childcare Partnership will assist others in progressing their plans for engaging with users. It has been our experience that quite a considerable amount of time and planning has to go into progressing this type of work. Perhaps the most important aspects to bear in mind are:

- Consulting with users is a two-way process (all parties must be clear about the overall aim and their potential contribution towards achieving that aim)
- It is worth stepping back and reconsidering your approach when information does not come back in the pre-supposed form (does further work need to be done on informing users?)

- Sometimes outside facilitators provide the clarity needed when information needs to be relayed in a jargon-free manner
- Consideration should be given to the additional resources needed in order to implement a User Involvement Strategy (ie, management and staff time, facilitator support, publications, etc).

I hope the above information is of assistance to others endeavouring to implement a User Involvement Strategy.

Underpinning Values, Not Words

Martin McCafferty

Manager, Creggan Day Centre

In trying to accurately and *honestly* describe 'personal' or user involvement in the planning and delivery of our services at Creggan Day Centre, I would like to first discuss the underpinning values of all our work with clients and families.

Although the words dignity, respect, inclusiveness and partnership fall off the tongue easily and are values we all believe we uphold, it is ultimately how the service user *feels* that matters.

I believe the key component to honest and effective involvement in all aspects of services lie in the relationship we have or can develop with each other; in effect, we need to understand better the 'realities' of each of our situations as well as the perceptions. A statutory Family Support Centre may for many be stigmatising, disempowering, directive and only concerned with a narrow legislative process, eg, re Child Protection. Yet even within this often contentious arena, the reality can be different and less monolithic or all-powerful.

The introduction of Family Group Conference which we share in, for example, provides a more equitable, respectful and inclusive process as opposed to the power imbalance of traditional approaches. It is this recognition of the individual, family and community's strengths and resilience which can be a powerful force for change and one which highlights true involvement and inclusion, even in the most challenging situations.

I would argue that *respect* is at the centre of this process and indeed at the centre of all inclusive processes. In my experience at Creggan Day Centre, the development and nurturing of respectful relationships in all areas of service provision can be a hugely effective process, both for improving practice and influencing service development.

A good example of this is our Day Care provision with individuals who have a dementia diagnosis. The relationships that have developed with individual service users, workers and their relatives/carers have provided the opportunity to influence the delivery of effective programmes, which 'feels' right.

The strong relationship that exists with staff and carers is transparently collaborative and

mutually respectful of each other's strengths. This involvement with carers and the resultant outcomes also feels 'right' for all concerned. Ongoing evaluation of services is also an essential tool in trying to determine how the services 'feel' for people, but frequently, service users will respond positively, even though they think otherwise.

It is getting a true and honest response that is the challenge, so it is essential to again give huge importance to the relationships we develop with everyone involved, from service users, carers, staff and management systems.

In many Health or Day Care resources like Creggan Day Centre, we have more regular contact and interaction with parents/carers, often on a daily basis. This helps us both develop a relationship that other professionals may not have. This 'closeness' gives the opportunity of identifying need and accurately advocating on behalf of individuals or, more importantly, helping them acquire the confidence and skills to do it themselves.

It is also this 'closeness' which gives us a true and more accurate awareness of peoples lives, their worries, concerns, fears and hopes. Many service users will often express gratitude and

satisfaction with our services, but when we honestly reflect on what we are offering, we often have to admit we should be doing more.

Many service users, particularly in our Children's Services Programme, will rarely question anything about the service they receive. Many of these families and children have had damaging and often destructive experiences which have hugely affected their confidence, self-esteem and feelings of self-worth. It is their views, their feelings, their experiences that need to be expressed, and even with help, if not by themselves, then by us or with us. It is this advocacy role that is vital if the feelings of those families and children are to be expressed or heard.

Day Care Groups

Mental Health Group

The group has a self-selected committee which meets on a monthly basis to discuss:

- Programme Content
- Evaluation of Services
- Individual issues, concerns.

The group has an impact on what services are currently provided and should provide in the

future. The total group also meets with staff on a monthly basis.

Dementia Day Care Group

We – that is, carers and staff – meet on a monthly basis. This is a forum that can be ‘informative’ and ‘therapeutic’ as carers and staff share experiences, ideas, etc in a supportive way.

It also provides opportunity for carers to influence service provision at the Day Centre.

Family and Children’s Services Group

We have regular evaluations of families’ views, feelings and ideas re service provision.

Currently, we are helping to set up a Service Users Committee to formally meet on a regular basis, to look at and represent views of families re service provision and development.

Examples of Good Practice

Kate McDaid

Assistant Director of Health Care, (Women & Children), Western Health and Social Care Trust

The Western Health and Social Care Trust (WHSCT), through one of its former legacy Trusts, established its local Maternity Services Liaison Committee (MSLC) in 1992. Key to the success of the Committee was user participation and ownership. Over the years, service users have been instrumental in shaping the development of the Western Trust's Maternity Services such as the introduction of water birth as an option for birth. Alternative complementary therapies such as reflexology and yogacise were developed as a result of users' demand for this service.

Questionnaires are distributed to service users when they are being discharged from hospitals to gauge on an ongoing basis the satisfaction of users' experience of the service. The Western Trust values customer feedback and is committed to developing and delivering services which are based around the particular needs of its patients and clients.

The community midwife collects the questionnaire from the service user ten days after she has been discharged from the hospital. The results of the questionnaire are collated and are reported on a quarterly basis. The report is distributed to MSLC (Mothers' Voice) and to the various professionals working across the range of maternity specialisms. The Maternity Services Liaison Committee reviews the reports and develops action plans based on feedback provided by the service users.

The feedback is also shared with mothers and service users through postcards which are displayed whilst on the Postnatal Ward.

Feedback is also obtained from Parent Education Classes and Postnatal Reunion Classes. The comments are collated and distributed to the Postnatal Group and MSLC.

Quarterly meetings are held in advance of the full MSLC meetings. These are normally attended by health professionals. A summary of issues to be addressed is drafted and issued to the Head of Midwifery within the Western Trust for consideration and for further discussion at the full meeting of the MSLC. This allows the Western Trust to develop and engage in meaningful two-way dialogue with service users

and to deliver service improvements based on the needs of women in local communities

This two-way feedback process enables us, as service providers, to continually improve services for patients in our local area.

User participation in service improvement projects

The following examples highlight the Western Trust's commitment to involving users to develop and deliver its Maternity Services.

Development of Maternal & Foetal Assessment Unit – A service user was a member of the project team along with midwives and obstetricians who attended planning days and meetings.

Developing Antenatal Care Excellence (DANCE) Project – A service user was a member of the project team with midwives and obstetricians attending planning days organised by the Clinical and Social Care Governance Unit, delivering Healthy Maternity Services.

Strategic project for new Maternity Unit – Service users have contributed to the design of the new unit and are involved in the selection of art work for the new unit.

The Western Health and Social Care Trust and Western Health and Social Services Board are developing a Maternal Mental Health Pathway and users have presented their experiences of postnatal depression at our Maternal Mental Health “Making Connections” Conference.

Currently, MSLC are designing information for women and fathers on recognising postnatal depression. The WHSSB have provided funding to MSLC Mothers’ Voice towards the design and print of these information leaflets.

In 2006, professionals and users organised a joint conference “Beyond the Blue Line”. This was an opportunity for midwives, obstetricians and users to showcase partnership working in improving services together in Altnagelvin.

Mothers’ Voice (MSLC) developed a Breastfeeding Network where mothers who recently gave birth provide their telephone numbers to newly delivered women who are breastfeeding. An information leaflet has been developed. This is given to all women on discharge.

The WHSSB provides funding to support the work of the local MSLC Mothers’ Voice. The Western Health and Social Care Trust provides secretarial

support for taking minutes at full quarterly meeting by the Business Support Officer. The Western Trust also covers costs for meeting room, crèche facilities, tea, coffee and scones in the Women's Centre, Guildhall Square, for user-only meetings and full committee meetings.

Women who attend the meetings get a nominal expense of £5 plus baby-sitting costs as an alternative to crèche provision.

The MSLC secured funding to undertake research to find out what local women wanted from Maternity Services. They commissioned the University of Ulster to undertake the research. Professionals and users were interviewed. In phase one, the key issues raised were summarised in an information leaflet and a number of focus groups were held with hard to reach groups ie Gingerbread, travellers, teenagers and those with a disability. The research entitled, 'Birth Matters' was launched on 4 October 2007. The findings will support the planning and provision of the Western Trust's Children's and Women's Services for the incoming years.

To improve user participation, MSLC Mothers' Voice organise media events and radio

interviews. Currently, MSLC are campaigning to recruit new users by targeting women's groups ie Surestart Projects and Derry Well Women.

User Involvement in a Community Enterprise Initiative

Conal McFeely

Creggan Enterprises, Ráth Mór

Meeting local needs through local ownership

Creggan Enterprises is not just about financial profit – it is also about the common good, which seeks to strengthen economic and social infrastructure, respects cultural diversity and embraces environmental protection of the community it services.

As a community-enterprise initiative, our social-economy approach is based on the belief that working collectively and in partnership with local people benefits people more than individuals working in isolation for private gain. Our value base is grounded in the principles of community self-help and development.

Our customers are the local residents and tenants of the Ráth Mór Shopping and Business Centres; they are the reason for our success to date. We firmly believe if we had not developed a community-based ethos, we could not have attracted the wide range of business and investment that we have over the past fifteen

years. Indeed, local user involvement has not only kept us in business, but has also been the catalyst that has renewed and improved our service provision.

We believe that all structures that provide a service should value users and acknowledge their observations and views. Working in partnership, we seek to deliver a high-quality service and programmes that meet local need.

The foundation to our understanding of user involvement is the ability to listen to our customer base and then to act on the information coming out of that process so we can plan further positive actions and outcomes. The building of user confidence and trust is key to success.

True user involvement is about mutual respect. We respect the user and hopefully the user will respect us in our endeavours to effect positive social and economic change.

In relation to our involvement with the Family Information Group, we have, over the years, developed an understanding which is totally user focused. This has resulted in improvements in how to deliver our products and services. The Family Information Group's wealth of skill and knowledge

has helped Creggan Enterprises enhance its approach to user involvement, particularly in the use of user-friendly and jargon-free language.

The Family Information Group also assisted us in the design of offices and units, which has ensured that all our facilities are accessible for those with disabilities, especially children.

For many organisations and groups, user involvement is simply a jargon concept. But for us, it is about solutions that meet people's needs. We place user involvement at the heart of our working methodology, as it is the outworking of our values and principles.

It makes economic sense, it is cost effective, but most importantly, it makes common sense.

Fundamental to our user involvement: our values and principles:

- Building an asset for community advancement
- Providing services to meet community needs
- Creating opportunities for positive community change
- Promotion of local skills and community ownership

- Generating financial and social profits for the community
- Nurturing new approaches in the interest of the community
- Being a pathway to inclusion.

Creggan Enterprises has fostered the benefits of partnership working between residents, public agencies, the European Union, the Social Economy and private sector to create pathways for investment, jobs and services to help address the needs of the area. We believe nothing lifts the morale of a community like the sight of abandoned land, redundant factories and buildings coming to life again.

It is only through investment in local communities and people that we will be able to address the social and economic needs of the community.

Our achievements and actions to date and mode of partnership working in developing the area have improved the environment and built a community infrastructure that has given individuals the opportunity to improve their employability and enhance community self-esteem.

We still have much to learn, particularly from those who use the Ráth Mór Centre.

User Involvement is About Users and Involvement

Brendan McKeever

Former Co-Chair of Homes Fit For Children Campaign

Being involved in the housing campaign to abolish the means test, 'Homes Fit For Children' changed my views on user involvement.

Through it, I realised that there are many different forms of user involvement, but there is something unique when such involvement creates real change. This article is about that type of user involvement that can lead to change. That is not saying that it is any less or more important than other forms.

But some people get lost in the politics of the campaign. They lose the essence, the core truths and the reality that no matter who actually started the campaign, it was about ordinary lives being lived out by ordinary people. At the beginning, it was not about politics, it was not about well-organised campaigns. In truth, perhaps in the early days, the term 'user involvement' was not even used by those directly involved in this campaign.

If we lose sight of the reality that user involvement is about people using services, then all the debates in the world on the subject will lead to nothing constructive. The housing campaign was about real people, about an issue that fundamentally affected their lives and which many believed at the time could never be addressed positively.

It was about users (which included parents), researchers, voluntary workers, occupational therapists and housing officials eventually working together to create change by providing information and evidence to politicians. Quite simply, it was people working very hard, over a period of years, to address a wrong – a wrong that adversely affected quite a number of families of disabled children, a wrong that had been accepted as a norm for years.

The wrong was that parents of disabled children were subject to a means test when they applied for a Disabled Facilities Grant (DFG) for their disabled child. The Grant, in this case, is to assist families to adapt their home to make it more accessible for their disabled child. Grants could only be issued if an Occupational Therapist assessed the need for an adaptation.

The means test did not reflect fully the family expenditure, particularly mortgage and expenses associated with the child's disability. Many parents could not afford the assessed contributions and as a result withdrew from the process, went into debt, took on additional mortgages – resulting in the disabled child missing out, despite the adaptation being for them. Also, despite the need for such an adaptation being assessed independently by an occupational therapist.

In the midst of all this, we can often overlook those who had no voice, those who had the most direct experience of the issue. In this case, disabled children were the users. It took many years for me to realise that the very fact that they used services meant, in essence, that they inspired the campaign for change. Indeed, they were the backbone. Without them, without their experience, there could have been no campaign.

But not just in this case; so often it is the actual users, those who daily live their lives using services, this is what user involvement is about. I feel as we delve deeper into this, the role of the user must be highlighted and stressed, or it will be lost in a sea of academia and research. You

cannot have user involvement without users, without their unique experience, without their expertise. If we have not learned that lesson from countless enquiries and inspections, then we have learned nothing. Not that users are always right; no, not that, but neither can their wealth of experience be overlooked and ignored.

Sometimes 'Homes Fit For Children' could be dismissed as a one-off, as something only relating to a specific grouping – disabled children and with no significance to anyone else – maybe even a fluke. This would be so easy to do. But time has proved that what happened during this campaign is not unique.

It happened before the campaign was born and it happened many times afterwards. It happens when people learn to appreciate their own worth, their own experiences; it happens when they find their own voice. It happens when people can work together, focused on an issue – even if this is from different perspectives, and where there is mutual respect. It happens when everyone involved is valued equally, no matter what his or her role is. It happens when user involvement is about users.

I am sometimes surprised when people say that this campaign has nothing to do with them,

even though they are in the Health and Social Care field. For some, it is the campaign and the bigger picture that jumps out. I then have to re-emphasise that this campaign started with researchers and people keenly interested in making a difference. It included parents of disabled children who knew nothing of politics and it challenged the established roles of professionals who never knew they could have an advocacy role.

This campaign showed that sometimes the most important role is to use services, or care for someone else who does. That experience, that role, can be the biggest contribution that someone can make – that is a very clear and real example of user involvement. In this case, not many disabled children and young people were on the campaign trail, but without them, we were going nowhere.

Politicians, through time, responded to all this, and after a number of years, there were dramatic outcomes in Northern Ireland, Wales and England:

- 2004 – means test abolished in Northern Ireland
- 2005 – means test abolished in Wales
- 2005 – means test abolished in England

But the most powerful outcomes were that those who once had no voice found one: that those who worked with families could work in partnership and advocate with them to create real change; that those directly using services could not only influence, but change positively those services they were receiving; that everyone had a role and everyone was of equal importance.

The quality of life of disabled children, young people and their families has been enhanced because of this campaign. Those involved have also been affected and many now believe that change is possible where beforehand it seemed like an elusive dream. It was hard work, it did take commitment, but most of all, it took users doing what they do best: living their lives. It meant those users being involved with others: involvement. This is what user involvement really means to me – users and involvement, not just one, both. Real positive change can then be made to happen.

User Involvement in Action

Siobhan McKeever

Parent/Claudy Special Needs Group

For me, as the parent of a disabled young person, and for other parents that I know who have disabled children and young people, getting together was what we did. Whether it was user involvement or not does not matter. We all live out in the country where it seemed that there are very few facilities for our children and young people. After getting together just to meet and chat and talk over things we had in common, we started a Group.

Now, we knew nothing about groups, organisations, management committees etc at the beginning. This was just our Group – the Claudy Special Needs Group, we called it, and we ran it with the help and support of a local health visitor. The local health visitor was very tuned into us, as she knew so many of us. As parents, we were very aware that unless we did something, no one else would.

The Group was started in response to the non-existence of recreational social and community activities in our local rural area. While there

existed resources for other children, they did not meet our Group member's needs. What had started off months previously as an evening get-together for like-minded parents had now come into a real Group that wanted action and were willing to do things for themselves.

In our nearest city, fifteen miles away, numerous special-needs groups existed, but transport facilities and general access was unavailable. The parents felt that their greatest need was support from other parents and carers who were experiencing similar problems. By meeting regularly in a local venue and participating in leisure and social activities, this enabled Group members to develop and nurture their self-esteem and Group cohesiveness.

Our parents felt they did belong. They felt confident talking to each other. We may not have seen ourselves as experts, but together we knew a lot about our children and young people and what we needed. This has been our great strength and what has kept many of us together for a number of years. We may not change the world, but we wanted to change *our* world, even a little bit.

From time to time, people from the local Health Trust would come and talk to us, come and listen

to what we were saying and doing. It appeared we were meeting local need in a way that others were quite eager to learn from.

This was about us as parents – maybe we are users, just identifying need and then doing something about it ourselves, driven by our own experiences. We all knew what life is like, what we had to face, what the issues were, but once we began to share this with each other, we helped change things for the better.

Of course, we may not have called it partnership working, but by working along with our health visitor, it became easier to change things. She knew the way things worked in her area of work; we knew what was important to us. Together, we did change things for the better and we found working face to face with someone we knew much easier than some unknown name almost fifteen miles away.

Over time, our plan of action included running activities for our disabled children and young people at different times, including the summer. We have regular meetings of our Group, which we still see as get-togethers, but we have also had sessions on cookery, arts and crafts and presentations made on subjects that interest us.

I am very proud of all the members in our Group. To some extent, we have found a voice, but more importantly, we have acted. We have done all this based on the wealth of experience we have as parents, and the welfare of our children has always been a priority.

I am not sure of all this user-involvement stuff. It does seem, at times, that it is a lot of talk. Our Group just do what we do best: we make a difference in our own little way. I would much rather have that than a whole lot of words that might sound good, but really say nothing.

An Ordinary Family with Extraordinary Challenges – A Family View

Tina McLaughlin
Parent

As young parents of a three-year-old daughter, we were excited by the birth of our healthy baby boy. We thought our worries were how we were going to cope with parenting, home life and going back to work just like every one else. How wrong I was!

My son was four months old when he began to bruise on different parts of his body. After taking him to the General Practitioner (GP) for the second time, the alarm bells began to ring; and after blood tests, he was diagnosed in the Royal Children's Hospital Belfast (RCHB) with severe haemophilia (A). This is a bleeding disorder due to the lack of clotting factor in his blood, making him bleed more easily.

It is a common misconception that people with haemophilia may bleed to death from the most minor cuts or nosebleeds. These types of bleed are a problem, but it is not this type of bleeding that causes the most difficulties, it is bleeding into the joints and muscles, resulting in excruciating

pain and long-term joint damage leading to chronic disability if not treated urgently.

Although bleeds can happen spontaneously, they are more common following injury; so, unlike children of his own age, my son needs constant supervision to keep him free of injury.

I am sorry to go into the workings of my son's condition, but I feel it is necessary to try and give a full picture of what our life is like. As a family unit, in the last five years we have come in contact with various service providers involved in my son's care.

I suppose you could say this is where user involvement began for us – and the lack of it. I would like to share with you some experiences we had to date, beginning first with my son's diagnosis. As you can imagine, it was a tremendous shock, even more so, as it is a hereditary condition that runs through my side of the family. It was a double shock, as I was tested years before and told I did not carry the affected gene; but mistakes happen.

Yes, we did have some help dealing with the diagnosis, but we were not prepared for the speed that our lives would change and

decisions that had to be made about our future in the space of a few days. Not to mention the grief I felt for the healthy child I had lost and the ordinary life we had before. I look back and wish there could have been someone in some profession that could have eased our worries and fears, but maybe this is something you have to face as a family alone.

My son is treated at the Royal Children's Hospital Belfast, seventy miles away from our home, although he is now on home treatment that requires injections of Factor 8 into a portercath in his chest. This has not always been the case; for the first three years of his life, we had to make the trip almost on a daily basis, day or night, to Belfast.

We can't complain, as the care we receive there is excellent. It is where I believe user involvement is at its best. We are treated as if our son is the only patient they have, and even at his young age, he is spoken to and not spoken about, and decisions about his care are always made with our involvement, I believe a lot could be learned from their example.

It may well be the case that it's because this is the centre of excellence for my son's condition

that it works well, But not all the professionals we come in contact with need to have the same level of expertise, just a willingness to involve parents. After all, we are the experts on our lives, our needs and our son's disorder.

I do not like to dwell on the negative attitudes, insensitive comments and discrimination, but we have faced them all over the years. This is not helpful to anyone, but we have learned the benefits of staying positive.

When it was time for my son to start nursery, our health visitor made an application to the Western Education and Library Board for a classroom assistant. We were horrified to learn there had been a meeting held and a decision reached without our involvement and he would not be considered for an assistant at this time. They wanted to try him in class and see how he managed.

But the only way to judge how he would manage was to see if he got injured. And we were not prepared to let this happen. In my opinion, this is a failure of user involvement: a bunch of professionals had made a decision on my son's future and failed to ask the experts (us).

The decision was put right at appeal, because they had information from us on our son's condition and needs. Had they done this to start with, it would have saved a lot of time, effort and resources.

These are just some of the examples that we have faced; there have been lots more, good and bad. We feel, as parents, that user involvement is paramount when making major decisions about our children's healthcare, education and family's future and maybe the best way to put an end to negative experiences.

User Involvement – Examples in the Community

Christy O'Donnell Parent

For those who don't know me, I am one small half of a parent/carer family. My wife and I care 24/7 for our beautiful daughter, who is profoundly disabled with cerebral palsy and with many other medical complications. She is the centre of our whole lives and, like many parent carers, we wouldn't change our situation for the world.

Caring for our daughter has brought our family and me right into this whole area of user involvement – not all the talk that surrounds it, but actually into real life, as we and so many other parents and carers know it.

I am sure some people, who have never really cared for a profoundly disabled child or young person, would wonder how I could say that we would not change our situation. Yet the openness to understanding how some parents feel like this, to me, is vital if user involvement is to work in practice. It is not whether people agree with me or not, it is that they accept that our experience. This experience has helped me to think this way.

Put another way, if I am expected to take on board the views, opinions and advice of those delivering a whole range of services, then the least that I expect is that my own views, those of my wife and those of my young daughter are equally respected and valued. In recent years, I feel this is happening more and more, but it has not always been that way. Our expertise, our knowledge has to be valued.

I will give you two real-life examples of where this has worked for us and those I live with in the Hazelbank and Ballymagroarty areas of Derry. The project is 'Families Caring Together'. From the outset, I would stress that the pilot project worked well because all of us involved worked together and we respected each other. Also, as users, we felt valued and not just that our experience of life was valued and helped shape the project.

Families Caring Together brought parents of disabled children and young people together with members from our local health and social services, including health promotion, a health visitor and those working on a specific health initiative called the Health Action Zone. The project was funded by the Health Action Zone.

The first initiative was a project that was tuned into the needs of families, as those involved listened to families. Those working on the project from a user background lived in the community, were sensitive to other families and were very aware of the issues. They were trusted by other families and they were able to reach out easily to these families. But they needed the other families to tell them what their priorities were. This was done by volunteers within the project.

What emerged was an opportunity for families to get a break; that gave parents and family members a chance to relax, knowing that a paid carer, who went out with them, would ensure their disabled child/young person was also being sensitively and safely looked after. A family night out? That seldom happened before, because the needs of their child/young person could not be met. Most did not want parents' meetings, rather just a chance to go out together as a family, just as many other families do.

Very simple but effective, and it took the families to identify this, and with the support from the health authorities, it happened. 'Respite', or short breaks usually, though not always, results in the parents being separated from the child/young person. This initiative was very different. Feedback from families was very positive.

The other example of user involvement I want to mention is the 'Caring for Carers' leaflet, which also stemmed from the Families Caring Together Project. This was another pilot project in the Hazelbank/Ballymagroarty area between Hazelbank Residents Action Association (HRAA) and the Health Action Zone (HAZ) supported by the local Health Promotion Department.

Our idea was to reach those parent carers who felt they were stressed and on their own. The leaflet was designed by carers for carers, and I know carers will identify with all that is in the leaflet.

Just as the family break was highlighted as being important, so too was information on how to deal with the daily pressures of caring. There are many different leaflets; our leaflet was to complement these, but we wanted ours to be clearly written and from the experiences of carers. Once again, we made efforts to really listen to carers, to hear what they had to say and to find out what their experiences of stress were. No big words, no medical terms, just what stress and/or pressure meant to them.

From this, we worked closely with our Health and Social Care workers and we put together a very powerful leaflet, with information and

contact details which would be helpful to any carer. Information on symptoms of stress, what to do about it and how to try to prevent it. Indeed, the leaflet could be used by many other people too, as its direct approach and very honest, straightforward language, based on real carers' experiences, is quite different from many other approaches to this subject.

Very simple ideas. But to me, this is what user involvement is about. Simple ideas, common sense, but very often ignored in the past. It makes sense that a family outing should be a family outing with everyone involved. It makes sense that if someone is producing information for carers that carers should be involved. It makes sense that users will work well with those who acknowledge their expertise and who will treat them with dignity and respect. Working together is much better than working on your own.

In our own way, where we live, we have shown – maybe in small ways – how user involvement can work on the ground. I believe we can build on this, but it takes hard work, commitment, perseverance and honesty – qualities we carers have been used to for years.

Finding a Voice

Mary O'Neill

Parent

In May 2006, I was asked to speak at a conference, the theme of which was 'Made to Measure'. It was run by ARC (Association for Real Change) and was well attended by organisations from across Northern Ireland who mainly deal with people with learning disabilities. The reason I was asked to speak was because I am the parent of a nineteen-year-old young person who has cerebral palsy and has a severe learning disability.

This was not the only reason I was asked to speak. For the previous year and a half, I had been involved in a campaign to highlight the lack of Speech and Language Therapy (SLT) in the Western Board area. I had first-hand knowledge of the situation, because my daughter required SLT but was receiving little to none on a whimsical basis.

I, along with countless other parents, foolishly believed that when we sent our children to a 'special' school that they would automatically receive every form of help that they required.

I was not aware that SLT was a Health issue and it was not the Education Board's responsibility to provide it.

I felt totally let down by the health system, but furthestmost I felt that I had let my child down by not fighting enough for her rights. Following a public meeting, Foyle Action Coalition was founded and I was asked to be chairperson. I agreed, not realising that what would follow would be countless meetings, endless cups of tea and sympathy and patronisation by members of statutory bodies telling us about how it was not their fault, that resources were an issue, lack of staff and countless other reasons as to why our children were not in receipt of such a key therapy.

As time went by, I was asked to sit on a steering group set up by the Northern Ireland Children's Commissioner (NICC) to review the provision of SLT across Northern Ireland. It was frustrating and at times hard to believe that the rights of children across NI were being neglected in such a way. I was naive in thinking that the NICC review would make a difference and, following a second review, the Regional Task Force for Northern Ireland was set up by the Minister for Health and I was asked to be a part of it.

Working with the professionals, Speech and Language Therapists (SLTs) and Allied Health Professionals (AHP), commissioners have made me realise that their job is made even tougher by the lack of resources and bureaucracy and it has made me appreciate the frustrations that they feel when they cannot provide a service to our children. At one meeting, I was once told by a board member, 'Wait till she gets to me, she'll get nothing'. I found this statement deeply worrying and upsetting and it made me all the more determined to carry on the campaign for SLT provision.

During the campaign, we had some success in that the Trust employed speech and language technical instructors, and while we were sceptical at the beginning, now, two years on, we are witnessing the work of the instructors on the ground. I realise that my child does not need one-to-one with a SLT but a well-devised programme that can be implemented by all professionals on a daily basis.

The theme of the conference was 'one size fits all'. My experience has taught me that this is not the case; every individual has his/her own needs and the parents/carers are at the face of daily living and therefore are just as able to input into the provision of services.

Attitudes towards those who care need to change. Our opinions are valid, and while we may not have the professional know-how, we can offer common sense approaches and valid opinions. It is by listening to the voices of carers in a non-condescending fashion that helps things to change.

Carers are under an immense amount of stress on a daily basis, and I am testimony to that. I am a committee member of Foyle Parents and Friends Association and over the past year we have been looking at the role of the carer and the impact of caring on the wider family network. We have raised funds and have been running events such as pamper sessions for carers to give something back to them and to help alleviate stress, even if only for a short period of time.

We have worked closely with the statutory bodies and we are in agreement that there is a general lack of awareness of the stress and pressures that carers regularly deal with. There are constant barriers, and as someone who is going through the Transition phase, I am only too aware of the stress that making choices that will affect my daughter for the rest of her life is immense.

Those involved in the Transition Process need to listen to the views of parents/carers and not just assume that they know the young person well enough to make a choice for them without even meeting the young person.

Those working in whatever profession should be aware that they are not only dealing with the young person, but need to be aware of the impact of their decisions on the wider family network.

By working with professionals, listening to the views of other carers and, more importantly, the views of the young people and their families, I have built up my own confidence and can now face whatever comes my way with a positive attitude. Life is about living and enjoying life as best as we can. By listening to the views of users/carers, professionals can gain a depth of knowledge that a textbook may never offer.

It is not an easy journey, and by realising that one size does not fit all, we can acknowledge the importance of the input from users/carers and parents and move forward without negative attitudes. And as far as I am concerned, we can only improve the lives of our young people by breaking down the barriers.

Youth Action Team and Involvement

Gillian Presho
Cedar Foundation

Children with disabilities and their families constantly experience barriers to the enjoyment of their basic human rights and to their inclusion in society. Their abilities are overlooked, their capacities are underestimated and their needs are given low priority.

The UN Convention on the Rights of the Child (CRC) recognises the human rights of all children, including those with disabilities. Article 12 states that Children and Young people have the right to express their opinion freely and to have that opinion taken into account in **any** matter or procedure affecting them.

Across all of the areas within the Children and Young People's service within the Cedar Foundation, we endeavour to ensure that the rights of the young people are paramount to our policies, strategic plans and service development.

As a team, we want to go beyond young people merely giving feedback on the services they

receive. Dr Roger Hart suggests, in his ladder model of participation, that the highest form of participation is through young person-initiated projects with decisions made jointly with adults.

These projects empower young people while at the same time enabling them to access and learn from the life experience of adults. This, according to Dr Hart, is the true nature of citizenship.

At each stage in the development and the delivery of all services within Children's service, the views of young people are central.

The Youth Action team is just one example of the user initiatives which exists within Children's services to facilitate the voice of young people to be heard, not only within the services provided at Cedar, but also the wider range of services for children with disabilities within the Health and Social Care Trusts. The Youth Action Team has had the opportunity to meet with planners from both the Western and Eastern Board areas.

Youth Action Teams have existed within Children and Young People's service at the Cedar Foundation for over seven years with twenty-five young people having had involvement.

The team meets with the youth officers in their area on a quarterly basis and is currently comprised of twenty young people who advocate on behalf of their peers within Cedar to put forward their ideas, opinions and feedback about the services they receive.

We aim to consult with our youth action team to ensure the services we provide best address the needs of young people with disabilities. We listen to, discuss and on occasion debate the wealth of ideas and suggestions put forward by the team's members; while I don't claim that our service is the epitome of true citizenship, what we, as a service, strive for is that the young people with whom we work have the opportunity to engage in increased, diverse and meaningful user involvement.

Public Involvement: The Big Lottery Fund Experience

**Walter Rader, Director NI, and Joanne McDowell, Head of Policy, Development and Public Affairs NI
Big Lottery Fund**

Big Lottery Fund (BIG) is committed to public involvement. Our mission is to bring real improvements to communities and the lives of people most in need. Without doubt, we cannot do this without having a clear understanding of those communities and their wants and needs. Involving people is also one of our six values: involving local communities in our work and making sure the public know and care about our work.

BIG aims to deliver intelligent funding, and we have developed a public-involvement strategy to help us achieve this. Intelligent funding means being responsive and flexible enough to adapt to changing circumstances. It also means establishing mechanisms to promote constructive debate and establish shared understanding.

Lottery money is public money – it exists because people play the National Lottery each week. There is a strong feeling that Lottery money is special,

that it is ‘the people’s money’ and that it should be used to make positive changes to the lives of people and local communities. Big Lottery Fund has a keen interest in ensuring that the public has confidence in the Lottery and are content with where the money is going.

The past five years have seen a wider shift towards involvement across government and the public sector, with a general expectation that every public institution involve its stakeholders in some way. There has also been an increasing shift towards local decision making, with people being given the opportunity, through mechanisms, to have a say on what happens in their local area. BIG has encompassed these opportunities to trial and embed public involvement our work.

Public involvement can deliver a range of benefits to BIG, to the projects BIG funds, and to the communities impacted on by those projects. Evidence for these benefits can be summarised into the following broad categories:

- Increased public awareness of and support for the Lottery
- Stronger projects with better outcomes
- Boosting confidence and developing social capital
- Better decisions.

Increased public awareness and support for the Lottery

Television has proven to be a useful medium through which Lottery distributors can reach wider audiences and raise awareness about Lottery good-causes funding. Viewer response to BIG's *People's Millions* Programme has been very encouraging and positive. It was delivered in partnership with ITV and has been very encouraging, with 500,000 votes cast in the project competitions held to date, the highest-ever number for this type of audience interaction through ITV's regional programming. Research conducted in the week of *People's Millions* £50K broadcasts and voting showed a 5% increase in awareness of BIG (34%) compared to the previous survey (29%) a few months earlier. Of those aware of *People's Millions*, 57% felt TV voting was a good way of getting a say and 34% felt the programme had made them more aware of Lottery funding for communities.

Stronger projects with better outcomes

BIG has long recognised the importance of local involvement and buy-in to projects. It is widely accepted that where people have a role in making decisions on a project, they will retain a longer-term interest in it. This is seen as particularly important for local projects, where

decisions are taken as close to grass-roots level as possible. However, this may also work on a wider scale. Where people are more involved in and aware of decisions on Lottery projects, they have more of an interest in the long-term survival of such projects and more awareness of those in their locality.

Projects too were generally positive about their experience of programmes such as the *People's Millions*. They felt that it had given them the opportunity to make their project known and, in some cases, attract other potential funders. The vast majority of the organisations taking part in the exercise welcomed the opportunity for the public to have a direct input into grant awards.

However, there was some unease about some of the aspects of self-promotion. In particular, there was a worry that larger organisations with greater resources automatically had an advantage. Also, that those projects with widespread appeal (for example – those organisations that work with children and animals) would be more likely to receive funding under this system than those organisations working on controversial projects (for example – with drug addicts, the homeless, young offenders, or migrant populations).

BIG's experience of supporting Healthy Living Centres illustrates a strong correlation between community engagement and project success. For example, the evaluation shows evidence of high levels of consensus in decision making, robust projects (despite setbacks) and high levels of sustained community engagement.

Boosting confidence and developing social capital

BIG's evaluation of Healthy Living Centres (HLCs) provides a wealth of evidence to demonstrate that public involvement helps to generate social capital in communities. Of the twenty-three projects examined in the evaluation, all have experienced social benefits of some kind, ranging from 'civic pride' through to improved access to facilities. Researchers found a number of examples where participation was the catalyst that brought about positive change for individuals. This change came in many forms including; employment, increased skills and confidence, improved mental health and in some cases escaping poverty.

The exercise of public involvement in a local community can in itself help to forge new partnerships and networks. For example, two-thirds of HLCs in the survey said that the impact

on the community could be seen in terms of the development of new networks to support the community.

Better decisions and better projects

Involving the 'community' in decision making allows us to create shared solutions, which respond to local need. For example, through the Young People's Fund (YPF) in Northern Ireland, BIG recruited young people, and supported them in their role, to decide on which projects should be considered for funding across Northern Ireland. This kind of engagement in decisions makes our decision making more responsive to beneficiaries.

The Fair Share Trust is delivered on BIG's behalf, in Northern Ireland, by the Community Foundation for NI. Communities in fair-share areas have the freedom to distribute funding based on their own priorities. The chosen fair-share areas are given a funding allocation. The local panel decide on local priorities and make recommendations on grants based on these priorities.

In conclusion, at BIG, we view public involvement as a package: a spectrum of activities that offers everyone the opportunity to have a say and to

shape our policies, programmes and processes. To date, we have recognised this spectrum of activity and have developed our learning through testing a range of approaches. We hope, through the evaluation of our current programmes and the development of future programmes, to further embed public involvement in our work.

Meeting the Communications' Challenge

Keavy Sharkey

Communications Practitioner

Introduction

Communication is a vital process. People have a need for and a right to information – the right information, at the right time, in the right format. Communication must be more than simply information provision. The challenge for communications' practitioners is to ensure that communication is a two-way process. Communication should be a two-way conversation – whether that conversation is between the state and its citizens, a retail outlet and its customers, a lecturer and his students, a doctor and her patient. The aim in producing this paper is to develop some thoughts around how these concepts of communication can be applied to user involvement.

Communications – an inescapable reality

Today, more than ever, we live in a society of communication – from face-to-face meetings to international conference calls that cross thousands of miles and several time zones, from telephone help lines to text-message updates, from leaflets and newsletters to interactive websites – virtually every piece of information can be expected to become an immediate object of communication.

The esteemed marketing academic, Philip Kotler (2001), writes that every organisation – be it in the private, public or voluntary sector – must communicate. In his mind, the question is not whether to communicate, but what to say, to whom and how often. Answering these questions presents a significant challenge for business, civil and community leaders, and much academic thinking has been published on how best these questions can be answered. For the purposes of the current paper, the focus will be on how some of this academic thinking can be applied to user involvement.

The communications' process

To bring communications back to the most basic level, we can look to the traditional model of the communications' process as illustrated in figure 1 (Jobber, 2001).

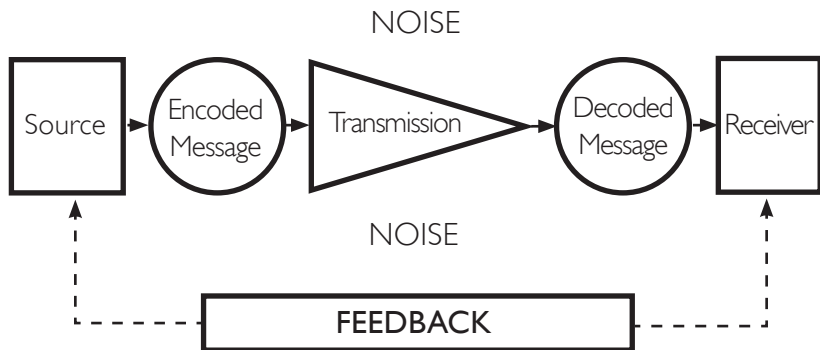


Figure 1: The Traditional Communications' Process (Jobber, 2001)

The model displays the process of communications in a few simple steps:

- Before sending the message, the ‘sender’ must identify the audience with what they wish to communicate
- The message is encoded by translating an idea into a symbol consisting of words, pictures or numbers
- The message is then transmitted through a choice of media – eg, a conversation, a website, a newsletter, a conference, etc
- The receiver decodes the message
- Feedback channels allow the sender to monitor responses.

The step-by-step process appears relatively simplistic – how could anyone get it wrong?

Our user-involvement scenario

A conceptual model of communications is all well and good in the academic world – but what happens if we apply it to a real life situation? In the Family Information Group’s ‘Information Project’, the following real-life scenario is presented:

“Take, for example, a parent whose child has just been diagnosed with a deteriorating condition,

out of the blue. The consultant has explained in detail the child's condition, but this is after giving the parent the devastating news – the parent does not hear, is not listening, is not receiving information.

“The parent is in shock, there may as well be no information provision. The parent is given a leaflet on the child's condition. Outside in the car park, the parent takes one look at the picture on the leaflet; this is not her child, the leaflet is torn up. There may as well be no information provision.”

Figure 2 presents an adaptation of the traditional model for communications for this scenario. Although the doctor knows the message he/she must communicate, and effectively does so through the means of a face-to-face conversation as the message moves through the communications' process to the parent, the message becomes confused, broken and potentially lost.

The process of feedback is very much reduced – because although the doctor may be willing to answer questions, the parent, who is numbed, in shock, frightened and confused, is unable to think of all the questions they will need to ask.

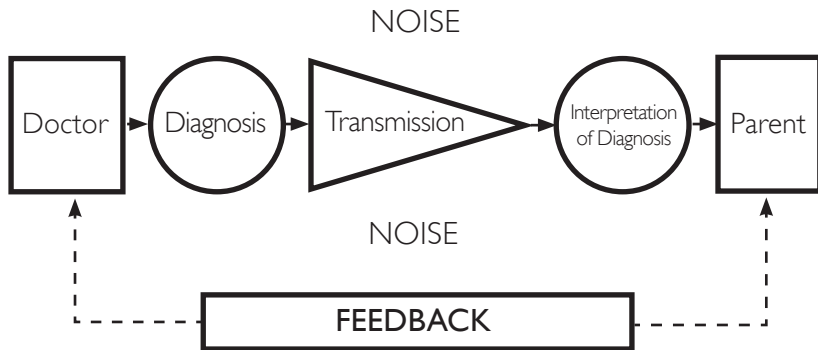


Figure 2: The Traditional Communications' Process adapted for our user-involvement scenario.

The Communications' Lessons

1. Understanding the receiver (the parent)

Understanding the receiver is crucial in an effective communications' process. The more the sender's field of experience overlaps with the receiver, the more effective the message is likely to be (Kotler, 2001). In other words, in our scenario, if the doctor has a better understanding of the parent's perspective, he/she could deliver their message in a more effective manner. There is little the doctor can do to alleviate the shock or fear the parent may be feeling, but small adjustments to their message delivery (such as using less medical language, providing a longer appointment, providing a follow-up appointment)

could help ensure that the parent receives the diagnosis with clearer understanding.

One means by which a doctor could develop a better understanding of the parent's perspective is to involve user/carer education as part of their continuous professional development.

2. Communications versus information overload

Doctors are under immense pressure: government targets, long waiting lists, constant scrutiny.

This pressure feeds into the communications' process – the doctor is under pressure to deliver and explain the diagnosis and explain what the next steps are for the parents. However, there is a danger that under pressure to deliver all this information, the doctor may sacrifice meaningful communication for what is simply the provision of vast amounts of information (Andersen, 2001).

Communication and information are not the same thing: to equate communication with information would be to presume that communication is simply a method by which a message is transferred from a sender to a receiver in accordance with the intentions of the sender. However, senders (in our scenario – the doctor) must be aware that during the communications' process, receivers (in our scenario – the parent) decode the message in their own way.

In our scenario, the doctor must give careful consideration to the information needs of the parents. Rather than partaking in information overload, the doctor must ensure that relevant, timely and easily understood information is provided. Only by carefully selecting, simplifying and summarising the data for transmission during the communications' process, can the doctor ensure that effective communication is achieved (Andersen, 2001).

3. Ensuring feedback

Communications should never be a one-way process. Ensuring a two-way conversation between the sender and the receiver is essential. Only by seeking feedback can the sender ensure that their message is timely, relevant and clearly understood. In our scenario, the feedback process is all but lost because the parent is too shocked, numbed or confused to take part in the two-way conversation. However, just because the two-way conversation does not take place at this stage does not mean it should be forgotten.

As highlighted by the Family Information Group's *Information Project*, once the family of a newly diagnosed child has had time to digest the news, they begin their search for information and understanding. In our scenario, the doctor should be aware that the parent will, at some point, want

to begin a two-way conversation. In this respect, preparations should be made to facilitate it – whether that is by follow-up appointments or by putting the parent in contact with an experienced user/carer information provider such as the Family Information Group.

The two-way conversation does not just benefit the parent, it also allows the doctor to develop a greater understanding of the parent's perspective (as highlighted in lesson 1), thereby helping the doctor to refine their message (as highlighted in lesson 2), allowing for better communication in the future.

The next communications' challenge

When the family of a newly diagnosed child is ready to begin the search for information and understanding, they often find themselves in a communications' environment that is saturated with competing messages from a range of stakeholders via a plethora of communications' channels – whether it's information conveyed at a medical appointment, information leaflets, telephone help lines or the internet. Navigating this saturated communications' environment presents the next communications' challenge in user/carer involvement. The Family Information Group's *Information Project* proposes a unique and sensitive answer to this challenge.

User Involvement in the Library Service

**Trisha Ward (writing in a personal capacity)
Library Service, WELB**

In Northern Ireland, the current governance arrangements as determined by legislation for 'public' libraries requires that each Education and Library Board establish a library committee made up of members of the Board who are identified public representatives (councillors), library interest members appointed through the public appointments process and representatives of different education sectors.

This group meets on a regular basis to advise and make decisions on library matters within the policies and framework set up by the Department of Culture, Arts and Leisure (DCAL). They agree priorities for the service, make decisions on areas of importance and monitor the implementation of these.

All of this has a direct bearing on the service offered by libraries. More recently, the Northern Ireland Assembly's Committee on Culture, Arts and Leisure (CAL) has been established to advise and assist the Minister for Culture, Arts and Leisure, Edwin Poots MLA, on

matters within his responsibility as Minister. The committee undertakes a scrutiny, policy-development and consultation role with respect to the Department of Culture, Arts and Leisure (DCAL) and plays a key role in the consideration and development of legislation. It is currently hearing evidence and making decisions about the future of libraries.

These public representatives, at a strategic level, represent the views of users and are directly involved in the development and delivery of library services. Probably most crucially, they control the 'purse strings', which, in a public body, effectively dictates many decisions. Political representatives might make the point that in a democratic society, this is an effective way to involve users.

However, some would say that the involvement of users, especially in decision making, should be about the involvement of customers.

One concern for libraries is that while we do (in WELB) have 1.1 million visits to libraries annually, the participation rate across the range of services is still lower than we would like. If we are to ensure more use, user involvement should also involve non-users.

So really, the main issues for libraries are similar to all publicly funded bodies: how can we effectively gauge the views of users and non-users across the range of sectoral interests (young, old, those from minority ethnic groups, those with a voice and those who choose not to engage with us)?

There are many tried and tested methodologies. DCAL engaged in a wide-ranging consultation prior to the publication of *Delivering Tomorrow's Libraries*, which forms the basis of current policy decisions. They also invest in omnibus surveys about specific issues like opening hours.

Public libraries use customer surveys like the Chartered Institute of Public Finance and Accountancy's (CIPFA's) *Public Library Users' Survey*, which can benchmark performance against UK standards and determine users' views on a range of issues. At a local level, WELB uses annual surveys of some customer groups (schools, local users) to determine a range of issues.

In 2006, Central Library in Foyle Street conducted a survey of over 1,000 teenagers. The response rate was good but the responses were mixed. Some people chose to respond to

only one or two questions on the survey, others chose to give such limited answers that only the simplest questions (yes and no) could be analysed.

The survey was costly and time consuming, and while the Library can say that it asked young people about what they wanted, it's not clear that the answers given reflected the views of a majority of young people in that age group. Following the survey, a number of invitations were sent out (to individuals who had responded, to local groups and to organisations) asking for participants in a focus group. A small incentive was used (£10 tokens for a local shop) in the follow-up phone calls and twelve people turned up. Their views were much more comprehensive, and as a result, a number of changes were made to the library.

In another aspect of library work, policy documents are now 'screened' to determine their impact on identified groups of people. This screening exercise includes requesting opinions on these policy decisions by special-interest groups. Once again, the exercise is sometimes fruitful – when groups engage with the Service to ensure policies reflect the needs of particular user groups.

In a more informal way, library staff will often seek the opinions of groups in developing and delivering services to, for example, early years' groups or to those who are visually impaired. Having an established group that is recognised as having some authority is a useful sounding board for consultation. This is where groups like the Family Information Group can have an important role.

This type of user involvement is about involving users who influence at both a strategic and an operational level. However, like the retail environment, libraries also involve users at a more fundamental level. In each library, members of staff deal on a daily basis with users. Their views are fed back through line management and can influence change. Comments and complaints made by the public are recorded and reported.

In a library service that includes the busiest library in terms of footfall in N Ireland, this should mean that we have no end of user involvement. However, with a growing number of users from minority ethnic groups who cannot always communicate easily with staff, increased use brings its own problems.

In reality, all forms of user involvement are challenging, and in a busy front-facing organisation, it is difficult to engage in a meaningful way.

Perhaps the message from all of this is that decisions are made by those who speak up.

Appendix 1 – User Involvement Article Guidelines

Please submit articles of approximately 1,000 words in plain accessible language (without jargon), via email, by 17 December 2007 to: b.mckeever1@ntlworld.com

These guidelines are just that, an indication of what has been requested. People experience user involvement in different ways, some do not realise that they are in user-involvement situations. The situations can be in different settings, consumer situations, Health and Social Care, education, training or a variety of others. Feel free to ignore the guidelines if you feel they do not apply to you, it is your experience that matters. But some people do want an idea of what this is about. This is it.

Guidelines

Aim – To raise awareness of user-involvement issues through a series of articles requested from a wide variety of sources.

Who? – The articles are aimed primarily at students and users who want to find out more about user involvement from different angles. They will also be used for a wider audience of anyone interested in this subject. The Family

Information Group aims to collect these articles and put them on its website and possibly publish them in web and/or printed form.

What? – Articles on the theme of user involvement **in clear accessible language that give different views/perceptions of this theme.** These are **not academic articles**, but any references to other sources should be included; if none are included this does not matter. Articles should be about **1,000 words** (two or three A4 pages).

When? – Articles should be submitted by email **by 17 December 2007.** Further articles may be requested at a later date if it is impossible to meet this deadline.

Where? – Please send articles by email to:
b.mckeever1@ntlworld.com

If this is not convenient, please contact Brendan McKeever at: Tel: 028 7128 5675

Why? – The core aim of the Family Information Group is that:
Those who use services should be involved in the planning and provision of services. The Group, therefore, has a vested interest in user-involvement issues.

There is a recognition that there is good practice in both statutory and voluntary agencies in certain areas in relation to user involvement; we need to learn from this. Some of these articles may give us an opportunity to do this. Some others have no real idea what this is about; the articles will address this. Others know a little about this and want to learn more; these contributions could help in this. It is hoped that by creating a better understanding of user issues and by learning from others that the culture of real user involvement, inclusiveness, will be developed.

The Article

This is basically **your view of user involvement**, how you see this topic from your direct or indirect experience. It could be as a user, as someone who works with users, in education, housing, health, Social Care, retail, consumer settings etc.

Your views on the following could be considered in the article:

- What is user involvement?
- What are user-involvement issues?
- Who are users and what do you call them?
 - service users, clients, citizens, customers, consumers, patients etc.

- Is user involvement important, does it have any value? And if what, describe this.
- What makes user involvement work best?
- What prevents user involvement from working best?
- Is there a culture that prevents user involvement happening? If so, describe this.
- Can user involvement lead to positive change? Describe.
- Your story in relation to user involvement.
- Your honest views on user involvement, any good or bad experiences and whether you think it can work.
- Can we learn from others – banks, retail, other consumers, schools, colleges and other walks of life?

Remember, this is your story, your view, your experience that you are being asked to share. By submitting the article, I will take it that you are giving your permission for us to use this appropriately. I believe a variety of experiences will help others to understand more fully 'user involvement'.

Appendix 2

Interpretation of DHSSPSNI circular on “Guidance on Strengthening Personal and Public Involvement in Health and Social Care.” (2007)

(Disclaimer: This information is not legally binding and is for guidance only and is based on an interpretation of PPI.)

On 26 April 2007, the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland endorsed Guidance on Strengthening Personal and Public Involvement in Health and Social Care (PPI). This was issued in September 2007 to Health and Social Care organisations across Northern Ireland as guidance under governance of duties in relation to public involvement and consultation. This is not new, according to DHSSPS, but the monitoring, regulation and accountability of it may be new to some people.

PPI is about:

- Involvement – more than consulting and informing. Includes engagement, active participation and partnership working.

- Personal – involving individuals who use services, including: service users, carers, patients, consumers, customers, relations, advocates or part of a group, such as a family.
- Public – involving the general public, locality, community, voluntary groups and other collective organisations (individuals, using services can also be part of the general public).

Health and Social Care Organisations:

- Current Health Boards (later Health and Social Care Authority)
- Health and Social Care Trusts
- Health and Social Care Council (later Patient Client Council)
- Family Practitioner Service
- Special Agencies.

Implications

The above organisations must:

- Have and demonstrate effective service-user and public involvement as central to their delivery of safe, high-quality services
- Involvement relates to planning, commissioning, delivering and evaluating services
- Ensure that all this is part of everyday practice

- Involve everyone in PPI – including staff on the ground, senior management, executive directors, board members and the chief executive
- Delegate someone at a very senior level to ensure all the appropriate duties are fulfilled
- Put measures in place that create inclusive conditions for involvement, including: effective communication (information in different formats, plain English, jargon free), support (training for staff and public – individuals and groups), practical help (transport, childcare, care support, expenses and payments) and pro-active engagement with others.

Ethos

PPI is about valuing experience, whether that experience comes from a worker, a user, a carer or a member of the public. It is about mutual respect, treating people with dignity, listening effectively, responding appropriately and about feedback and outcomes. PPI will not work unless there is commitment, resources, openness, transparency and unless it is founded on acknowledging diversity, and ensuring that partnership working and collaboration underpin all the duties. It will take a change in culture, but there are many excellent examples where this is already working, even if it is not called PPI.

Will PPI Work?

Time will tell. However, all this is not an aspiration; it is a duty. As such, it will be led by some of the most senior members of organisations. It affects everyone in Health and Social Care organisations, and everyone is accountable. There will be measurable aims and objectives, self-evaluation and outside inspections with the Regulation and Quality Improvement Authority having a key role.

Immediate, short-term and long-term action plans will be drawn up with specific people leading on certain duties. For probably the first time, Health and Social Care will be regulated on user involvement. It is the hope of the Family Information Group that users will also be directly involved in this monitoring and evaluation. Then it just might work.

Conclusion

The Review of Public Administration certainly has caused some apprehension among Health and Social Care staff. However, it also has created real opportunities for change, which this initiative is part of. Users generally do value and respect staff and would be very willing to collaboratively work with them on positive changes which could lead to better services. No-one will say it is easy.

In the end, we all want the same thing: an improvement in the quality of services. It is a challenge for all of us, but with commitment, with resources and with mutual respect and an acknowledgement that we are all experts with something to share, maybe we can change the culture.

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