

USER Involvement

More Than Words

BRENDAN Mc KEEVER

GUILDHALL PRESS

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It would be impossible for me to acknowledge all those people over the years who have helped in my understanding and appreciation of user involvement. There are too many. I hope that everyone who knows me and has been involved with me and the Family Information Group will realise that, even though their name is not mentioned, I still appreciate and acknowledge their expertise and support.

Our personal experience with our son Donovan brought us into contact with many caring, sensitive and supportive health and social care professionals, long before we ever really knew about user involvement. Yet through them we learnt the importance of being engaged as individuals, of being listened to and having our views and experience taken on board in our care of Donovan. Thanks to all of them.

When the Family Information Group was formed, user involvement began to make sense and those families and relatives involved are acknowledged, although there are too many to mention, including a hard-working and supportive management committee. But I would like to thank specifically Breige McLaughlin who so ably supported our administrative work and prepared our many publications over the years. Also several years ago, one of the most influential parents in our group, Christy O'Donnell, passed away. He was an inspiration to me and our entire group and always kept us focused on the key issues.

I would also acknowledge those in the community who worked so positively with us, particularly Martin McCafferty, Siobhan Livingstone, Paraig O'Brien, Liam Harrigan, Gerry Conway, Michael Dobbins and those who worked in the Creggan community in various organisations.

Locally, other groups and individuals were very encouraging and supportive such as the parents in 'Special Schools', support organisations and even those not involved in disability issues. Organisations such as Creggan Early Years Network with Maura Mason; the Irish language group Altram, spurred on by Danny Cassidy; and Bridgeen McGlinchey who from the earliest stage supported and encouraged us, despite being in a very different field of work. I believe both Danny and Bridgeen opened our eyes to the importance

of the human side of our work but also helped me understand that marginalised individuals and groups have so much in common.

Another very influential supporter and influence from the past and in the present is Conal McFeely of Creggan Enterprises. All of these, along with regional organisations supporting carers, parents and children contributed to our understanding and my own personal appreciation of user involvement.

While at the height of our influence, the group supported the 'Homes Fit For Children' housing campaign, which has been featured as an example of good practice in this book. Individuals, families, groups, organisations, housing and health professionals, researchers, campaigners and politicians helped to take user involvement to a new level with the campaign to abolish the means test associated with the Disabled Facilities Grant.

It was a long hard struggle but we got through it and as a result user involvement came of age. All of us involved in this were impacted greatly and thanks are due to all those who participated in this campaign at whatever level, they helped make user involvement real.

Special mention has to be made of Frances Heywood, Keith Bowen, Ginnie Shaw, Alison Jarvis (Joseph Rowntree Foundation) and Jackie Hughes who helped drive the campaign. Those associated with housing issues such as Paraig O'Brien, Willie Carlin, Sean Cassidy and David Crothers also played a critical role in addressing the issues in the campaign.

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Throughout the years also the local press and media including BBC NI and UTV were very supportive of our work in a sensitive and positive way which helped a lot.

Just when I thought we had gone as far as we could, yet another level of user involvement was opened up in the universities and colleges of further education. Staff in the Social Work departments were instrumental in opening this door for me and helped me explore different approaches to user involvement.

This work is ongoing for over 15 years and although demanding at times it is very rewarding. Again I must mention specifically Huw Griffiths (Magee Campus, Ulster University), Joe Duffy (Queen's University), and Gerry Skelton (Belfast Metropolitan College) and their colleagues in the field of user involvement in social work education.

As opportunities came along for me to avail of public appointments, user involvement became a focus in a different way. As a member of the Northern Ireland Social Care Council (NISCC), the overseeing body for social work and social care, I learned a lot more about such involvement. Council staff and members – particularly the sensitive and very supportive chair Jeremy Harbison and Chief Executive Brendan Johnston – were very helpful and offered me many opportunities to develop skills and understanding.

There was yet another twist when I became a Non-Executive Director of the Health and Social Care Board in 2009. The board currently commissions health and social care services in Northern Ireland. Although its remit is far beyond involvement, it does have an obligation under legislation in relation to this. At various times the board, its officers and members have been very supportive and sensitive of my perspective of involvement, especially the chair Ian Clements, Fionnuala McAndrew and Jacqueline Magee.

Through this work I have been engaged with the Public Health Agency which promotes good health in Northern Ireland. I wish to acknowledge the staff and management in this agency and the board, particularly those involved in the 10,000 Voices initiative and 10,000 More Voices and work on Personal and Public Involvement.

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There were people within Foyle Trust and the Western Board (as it was known then) and several other agencies that funded our group over the years. We appreciate the financial, moral and general support given to us by all of you – there are just too many to mention but you know who you are and thanks. But I do have to mention specifically Tom Haverty, Noel Quigley, Stella Burnside and Elaine Way, their help was critical, particularly in the early days as we tried to find our voice.

All my work around involvement would never have been possible without the continued support of my family. I would like to thank them most of all – Teresa, my wife, who has been more than tolerant of me as I pursued my dreams; Ruth, my daughter, for all the technical support and guidance; and Jack my son. Without them I would have learned nothing at all.

Finally, I have to acknowledge our oldest son, Donovan. His legacy is my understanding of involvement, without him and my family all this would be meaningless. I acknowledge him and everyone else who have made this personal reflection on user involvement possible. User involvement is about living life and engaging with others, and this book simply reflects my thoughts on these important issues.

ABOUT THE AUTHOR

Brendan Mc Keever has been involved in user issues for over 25 years. From when his son, Donovan, was diagnosed with a disabling condition in 1991, both he and his wife Teresa were advocates for and with Donovan on health, social care, education, housing and many other issues. User involvement was not a theory for them but an everyday reality. With other parents of disabled children, family, friends and several professionals working in health and social care, he helped to found an advocacy organisation, the Family Information Group, in the late 1990s, promoting the family view of disability.

As a result of this work, Brendan has written and had published a number of books on the issues that impact families. Later he was invited to become involved in a housing campaign, 'Homes Fit For Children', to remove barriers to accessible housing for disabled children. Brendan led up this successful campaign in Northern Ireland.

Although now semi-retired, Brendan has still a keen interest in user involvement and health and social care issues and is currently a board member, by public appointment, in a regional health and social care organisation.

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FOREWORD

I consider it a privilege to write this foreword by way of introduction to Brendan Mc Keever's book on user involvement. I first met Brendan in 2003 when I was setting out on my own journey of trying to understand service user and carer involvement. The late Dr Jeremy Harbison, in his then role as Northern Ireland Social Care Council chair, suggested I speak with Brendan as a first point of contact in my attempts to further my understanding of this area.

We subsequently met in Magee Campus, Ulster University, where I worked at that time. I was immediately struck by the passion of Brendan and his unswerving commitment to the topic of user involvement. He wanted assurance from me that this had to be more than an academic pursuit on my part, that for this to be 'real', I had to submerge myself very deeply into the topic.

Brendan used the metaphor of user involvement being like a well that should not be visited for occasional sips of water but a well into which one had to be fully submerged in order to fully appreciate what involvement really means. This made me realise that this topic was 'more than words' and, some 16 years later, I can think of many times when I was in the well of user involvement in my attempts to deepen my understanding of its real meaning. Brendan Mc Keever has been my compass on this journey and I have learned immensely from him over many education and research projects we have worked on together. It is no accident that my PhD, awarded in 2014, is titled 'Drinking from the Well'!

This book will, therefore, afford the reader the opportunity to also enhance their understanding of what user involvement means as it is written from the perspective of a person who has lived it. Brendan takes the reader on a very personal journey through his experiences of how his understanding in this field has developed over a lengthy time period. Many examples are provided of how the subject of user involvement has evolved and these are accompanied by Brendan's observations and commentary on the important related issues. The reader, therefore, has the opportunity to both personally experience

Brendan's work, efforts and methods to ensure that user involvement is fully grasped and is also provided with a current appreciation of where user involvement currently fits in the contexts of policy, research and education.

I have no doubt that Brendan Mc Keever's book will add significantly to an immersive and insightful understanding of user involvement. It will be a key resource for anybody who wants to understand user involvement, such is the care, emotion, genuineness and honesty that Brendan has brought to the topic. This, therefore, is a very welcome publication and addition to the literature in this important field.

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INTRODUCTION

User Involvement: More Than Words is a viewpoint of involvement, a personal analysis, from a user background, because that is where I come from. There are other ways of looking at user involvement – from the point of view of those who plan and deliver services, from academics who work with users in the field of higher education or from people who in reality know little about the subject but think they know a lot. It is only occasionally that users themselves describe and analyse their own situation. Perhaps now it is timely to look at user issues in this way. This is what this book is about, this is the perspective taken, the user perspective.

There are a number of definitions and terms associated with involvement and often there are differences of opinions over these. To simplify issues, in this book, the term ‘user’ refers to those who directly use services as well as those who care voluntarily for those who use services (carers). Most of the involvement featured in this book is in relation to housing, health and social care. But it is important to point out that user involvement can be in relation to many other services.

The purpose of this book is, as the title suggests, to make user involvement more than words. It is intended to do this by identifying real-life experiences that illustrate the working out of user involvement in practice, featuring different views and perspectives, and highlighting models of good practice. It is hoped that all of these will contribute to an understanding of the reality of user involvement. But what is most important is that in the context of this book, user involvement cannot work if users are not involved in some way.

What, then, is user involvement? It is the involvement of users in the planning and provision of services, whether this involvement is from the individual, family, group or wider community.

It is intended that the reality of the user experience will be illustrated in this book. Increasingly, in some circles, there is a tendency to discuss user issues with no real reference to actual users’ experiences. There is a possibility that user involvement could become an academic topic, analysed, studied and debated but void of any real

practical experience, where there is no place for users, although in Northern Ireland sensitive lecturers and researchers will ensure that this is not the case here.

In the community and voluntary sector there are many organisations which represent users and their views. Important as this is, it is equally vital to seek out and engage users themselves, to get their views, particularly if they are individuals or in groups that are seldom heard, often left out or are not part of a consultation process which makes them among the most marginalised because usually they have no voice. It may take more effort or a different set of skills, but to be inclusive, real attempts should be made to listen to, and act on, those voices.

Certainly user involvement has a key place in our universities, academic institutions and within the health and social care field, but so should users. User involvement cannot be sanitised of users just to meet specific criteria, just to fit in with specific programmes or just because it is too demanding or maybe we just could not be bothered. The challenge of user involvement is based on how we engage inclusively with users, without them all theories and analysis are flawed. We may have very interesting debates and discussions, but that is all we will have without true engagement. Trusting relationships between all involved in these processes can often help address any of these concerns.

As user involvement or variations of this become more prominent in diverse areas of our life, there is yet another danger. This danger is that the core value intrinsic in user involvement, that working in partnership can create positive change, is forgotten or overlooked. Sometimes there is no 'feel' for what is actually going on; we may be more interested in being seen to do things than actually doing them. Or such involvement could be seen as a passing fad, the latest 'in thing' which will soon disappear along with all the other 'well meaning' initiatives and as a result not worth bothering about.

Involvement can also sometimes be replaced by a tick-box mentality, fulfilling statutory obligations but not knowing why. The task or exercise is more important than how they are done. Consultations are an example of how to engage, but only if responses are acted

upon. Indeed, some critics would argue that at times decisions are made prior to the consultations.

This book is targeted at a wide range of people including users, academics, students, staff and management of health, social care and housing agencies and anyone at an academic or practical level with an interest in user involvement.

BACKGROUND

User involvement is not new. It has appeared in different forms over the years – partnership working, inclusion, Citizen’s Charter, Patient and Client Involvement, Personal and Public Involvement, Community Development etc.

Both statutory and voluntary agencies have demonstrated that user involvement can work, and work effectively. This has resulted in the accumulation of positive evidence and encouraging feedback over time from a variety of projects.

But we should remember that this did not happen overnight, it has been a long process. The concept of user involvement has emerged gradually over time. Social researchers and historians will trace its development perhaps from different angles and perceptions but nonetheless it has now come of age and currently is a fundamental challenge to traditional ways of working.

Prior to the 1960s, there was a tendency to respect authority without question. Authority (political, social, church etc) was always right and authority was always respected or should be respected. This was a time when expertise related to your status in society as opposed to knowledge and experience. It was a time when many people on the margins of society had no ‘voice’ and no access to those who made decisions impacting their lives.

The overriding philosophy of the time would have been: ‘This is the way things were, the way things are and the way they will be.’ An arrogant barrier to any change. Even today there are people who adhere to those outdated sentiments.

With the sixties came social challenge and real change. Teenagers were emerging as a significant and distinct demographic with their own values and beliefs, often completely contradictory to those of their parents. Emerging civil rights campaigns were asserting a new agenda as prejudice and injustice were scrutinised and challenged.

More inclusive education opened the doors of universities to students from different backgrounds; they were no longer the home of the elite. Through university study many young people were given opportunities to question, to challenge and to embrace new ideas

and cultures. Some of these political and social activists would later become influential leaders across the spectrum of society.

Alongside this, the media was becoming a platform to debate, to investigate and to scrutinise. The printed press and broadcasters were open to asking questions, carrying out inquiries, challenging the status quo and publicising their findings. A radical type of investigative journalism emerged which became part of the mainstream news but which also developed into hard-hitting documentaries and films.

Some of these reports and documentaries helped give voice to many who in the past had been marginalised by society. It was becoming an uncomfortable time for the traditionalists.

The term 'consumer' came to popularity in Britain in the early 1960s to initially describe those who bought commercial goods and services. The term was increasingly applied to those who accessed public health and social care services. In the 1980s, in response to this development, the Citizen's Charter in Health and Social Care was established. This charter included a consumer line to feedback to local health and social care planners as well as the development of measurable guidelines for health and social care services.

Increasingly, however, reports, inquiries and research were finding that sometimes the so-called 'experts' were getting it wrong and, worse still, were covering this up. The findings and recommendations from a number of these reports began to reshape the way some services were delivered and most importantly a sense of accountability began to raise its head.

Rights began to emerge and were incorporated into legislation which in turn helped to protect the rights of those receiving services, as service providers began to be held to account. Parallel to this in health and social care there was awareness that users also had expertise and knowledge as they actually used the services. So not only had they rights, they had experience.

These developments set the scene for potential engagement between users and those who planned and delivered services.

User Perspective

It has to be stressed that the user perspective is just that, a view, a perspective. We may not agree with it; we may not buy into everything that has been said but nevertheless it is valid. The reason it is valid is because it is life as seen by some users.

Recent changes, particularly in health and social care, have impacted the powers, authority, confidence and esteem of many front-line workers. When jobs, careers and roles are changing and are sometimes at risk, and when pressures at work increase, this can create a negative impact on staff and relationships with users. Staff may feel isolated and less willing to engage.

Although perspectives can obviously vary, it is only through sharing these perspectives that users can interact with those who plan, design and deliver services. Sometimes experiences can be positive, other times they are negative. But through them users have an insight into services that often those planning and delivering services cannot have.

The commercial retail sector has known the importance of users (customers) for years, and tried to respond to them positively. The planning, design and delivery of commercial services to customers has reflected customers' views, feedback and concerns particularly in the past ten to 20 years. Customer care has become a growing business in itself and various methods of gauging consumer views have been tried and tested.

Health and social care are, on the face of it, different from the retail sector. Most people who access health and social care services do not have the same degree of choice as in the commercial sector. This is particularly true in relation to choice of services or indeed the personnel involved. There are usually no refunds or services on approval. Only occasionally are services paid for up front by service users and seldom is there competition among service providers.

However, despite all these differences, lessons can be learned from the retail sector, vital lessons in how to treat and listen to people who use services.

An example of a creative response to partnership working has been the development of appointment systems in some of our hospitals.

For many years appointments were just sent out to patients and the timing of these were to suit those making appointments rather than for those due to attend.

As concerns arose over missed appointments and cancellations, views of hospital patients and staff were sought. It seemed that appointments were being made at inconvenient times. Staff and management were also willing to change as the old system was just not working efficiently.

Changes were made – patients were given a choice of times and dates for appointments. Although there are still cancellations and missed appointments, it is generally believed that the current system is much more efficient and user friendly. The experience of patients and an openness to do things differently led to positive change. Delivering services sometimes can be different from receiving them.

The minuscule details that impact users' lives are important and often can be part of a specialist type of involvement in sub-groups or special interest groups as the practical issues around user involvement are discussed. For example, those who avail of cancer services, disability services, children's services, older people services etc can have a meaningful insight to such services and therefore have much to offer those designing and planning them in these particular specialist areas.

There are many other areas of involvement, however, where specialism does not apply. But being a user is equally important when issues such as working in partnership, developing, planning, designing and delivering services are being considered. These issues simply require the engagement and involvement of users with their general rather than specific experience.

Being a user with that background knowledge and experience can be a great asset when working at a strategic level while knowledge and experience of a specific condition can equally be of value when working to enhance and develop services. These are complimentary and not in competition and depend on the circumstances.

What's It All About?

This is a key question that needs to be addressed. Sometimes it appears, if you are a user, it is as if people are doing you a favour by trying to engage with you or consulting with you over an issue. It is important, therefore, that clarity is achieved as to how user involvement is implemented and what is expected of the various participants in the process.

For many users there is a degree of scepticism when it comes to engagement, particularly when it comes to what the process is about. Some may feel that their involvement is tokenistic, simply being there for the sake of being there rather than being fully engaged. Sometimes the call goes out for a user to be on a committee or group without any thought given as to how this can be facilitated and how the user can be supported if he/she decides to become involved.

Again there can be a reluctance to engage when it is felt that decisions have already been made in advance of any involvement. It is not easy to overcome these apprehensions but an awareness of them in advance of any engagement process may help. However, positive engagement exercises can help to overcome these barriers through time.

For a variety of reasons it may not be possible to respond to all inputs, there may be restrictions around budgets, protocol, policy and legislation. But if there is real engagement, if people know what they are involved in, then even if the outcomes may not be exactly what they would have wanted, they appreciate this and are not put off. The reality remains, however, that some users just do not want to get involved, for a variety of reasons, maybe they just do not have the time, and this should be respected.

User involvement relates to the ability to listen to users, staff and planners whose views should be taken on board when future services are planned and delivered. It is also about facilitating involvement by all who should be involved, an inclusive approach that is supported in a variety of ways.

The involvement process is not an end in itself, powerful though it may be. Involvement is about change, about higher quality safer

services, about doing things differently, it is about making a difference. When experiences and knowledge are shared and equally valued then the potential to meet these aims and expectations can be reached. In reality, user involvement is about an inclusive approach to improvement of service provision. But it does not start with a blank sheet.

It is recognised and accepted that many of us come to user involvement with our own histories, attitudes and perhaps even prejudices. These in themselves could prevent real involvement and engagement or conversely may even facilitate such involvement. What tools, therefore, do we use to engage? To many, the first that comes to mind is consultation. There are many angles to consultation and although it can be a very effective tool, sometimes it can create more problems than it solves.

The main problem with consultation is that often individuals can be the subject of too much of it, leading to what is termed 'consultation fatigue'. This problem can be exacerbated if there is a perception that, despite the constant discussions, the issues and voices of those consulted are not even being listened to or taken on board. So how to engage?

If engagement and involvement are so important, and can reap numerous benefits, it is imperative that we build upon our own knowledge and skills and learn to engage in a more effective way. One of the best ways to do this is to look at best practice, to study what has worked in the past. We should also examine *why* the process has worked as well as analyse the results and outcomes.

It is also important to learn from what has *not* worked in the past. We would be losing out on a lot of beneficial groundwork if we ignored the wealth of information and examples of good practice already available which would give us a good start in honing our user involvement engagement skills.

Some research and reports are increasingly being influenced, and even occasionally written, by users themselves, as well as academics and social researchers, and these hold a wealth of information which again can be useful tools. This type of information is often compiled through reflective practice and evaluation and through considered debate and discussion which makes it so valuable.

Another useful academic tool to potentially improve engagement and involvement is based on what is called an 'action research' model of work. This entails planning an event or task as inclusively as possible, carrying it out, then evaluating the results. Having analysed any issues and absorbed any lessons learned, then the task or event should be run and evaluated once more. This process should be repeated until any barriers and impediments to inclusive engagement are identified and addressed which should lead to a better form of involvement. Again, this approach is based on reflective practice and evaluation, critical tools in themselves.

Finally, our own practical experience (if any) of involvement and engagement can be a sound teacher. We can translate lessons learned into our planning for engagement. This is the common-sense approach, something that so often we ignore.

A PERSONAL VIEWPOINT

Most people live private lives, seldom seeking attention outside their immediate safe circle or wanting to bring attention to themselves, believing their daily routines to be of little interest to others.

Yet it is in that personal reality of life that we get most of our experience and knowledge, most of the expertise we need to get through life. We often take for granted simple things such as how we relate to others, our own particular family experience, how we conduct our business of life, how we deal with the small things, how we face the major decisions and choices.

But what happens when something unexpectedly arises which creates a whole new experience of life which you have no skills or knowledge to deal with, or so it seems. The user experience can be like that. It can seem so personal and individual. Sometimes the emphasis on groups and representative bodies can overshadow this individual experience and knowledge, but this does not lessen the relevance and importance of the individual.

The day our son Donovan was diagnosed in 1991 with a life-threatening disabling condition was just like that, and he was only four years old at the time. We did not then fully understand the implications of his diagnosis of Duchenne Muscular Dystrophy. But immediately, almost overnight, our lives changed completely.

Increasingly we felt isolated and marginalised from many of those around us, believing that no-one could understand how we felt. Our world had fallen apart and no-one could feel the pain that we had. Of course, in hindsight, we now understand that many people have their own pain and sometimes it is far worse than ours was. But back then we were locked in and totally focused on our own hurt.

Gradually we started to live with our new situation and although we could not initially articulate our feelings about the health, education, housing and social services we were availing of, we began to learn that sometimes we saw things differently. This was no reflection on the sensitive, caring professionals involved with us.

We questioned why Donovan's diagnosis confirmation had to be in Belfast with all the added pressure that put on us travelling and

having then to break the news to relatives and friends when we got home, shattered. Why could this not be done locally? Back then, that is the way things were done. Today, consultants can carry out the diagnosis locally in clinics or even sometimes in the person's home. This would have seemed impossible all those years ago, even though it seemed common sense to us.

A whole range of health services and professionals were on offer to us such as physiotherapy, occupational therapy, dietary advice, social work, medical consultant etc and at first these were very intensive. This meant my wife and I taking a lot of time off work to go to these appointments and they were all in different venues on different days across the city. It would have made sense to have them all in the one place on the same day and eventually that is what happened. It is called multi-disciplinary working and eventually was carried out in a local clinic. Although we and others may not have driven these changes, it is interesting that from our perspective that these changes made common sense and it was our experience and that of others who understood this, long before change occurred. We were living the experience and it was real.

Many parents of sick and/or disabled children often have to fight for their child and the services they require. Fight may be too strong a word, sometimes it is advocacy or speaking out, but certainly on occasion more forceful actions may be needed. Young children have minimal capacity to voice their own concerns so it is left to their parents to speak out on their behalf. The pressure is often on the parents because if they do not raise issues, very few others will. This is where sensitive professionals prove their worth and we were so lucky to have a number of these assisting and advising us.

As Donovan got older and became dependent on using a wheelchair this brought us new experiences and challenges. But gradually we were also changing, valuing the here and now, not looking too far into the future and rather than put all our energies into finding a cure, just live for the moment. This is how we learned to live with our new situation. There was one more important lesson, we began to try and see things through Donovan's eyes and not so much ours, and this helped a lot.

Of course this is very personal to me and our family. What really has it do with user involvement?

In my opinion it has all to do with user involvement because such involvement is about valuing your own experience and knowledge. It is about sharing these with others, particularly those who work with you. Also it is about creating positive change together and being involved.

In our situation it was about our disabled son, but it could be about someone with cancer, dementia or a stroke. Or indeed about someone accessing hospital services. Anyone who accesses the range of services in health, social care, housing, education etc has the potential to become part of user involvement.

Drawing on the experience of Donovan's life and ours, I had something to share, from a user perspective, with social work students, housing officials, Health Trust staff and academics that were willing to listen.

Today that individual personal experience is part of what is called Personal and Public Involvement (PPI) in Northern Ireland statutory health and social care. However, sometimes this can be overlooked. PPI is the term used by some NI statutory health and social care organisations and agencies to describe how they engage with and care for those who use services – individuals, groups and the wider community. What we tend to forget is that the collective experience, the public and community perspective (the public aspect of PPI) emanates from a collection of individual experiences.

The lone single voice can be as powerful and influential as the collective one. But this can be strengthened if there is sensitive facilitation and the collective public voice incorporates this, rather than ignoring it. There is space for the public and the personal within the involvement process even though in recent times the individual voice does not seem to be as much to the fore as it should be.

In my work with families of disabled children, I never ceased to be amazed at the personal expertise and knowledge these families gained from their life experiences and many of them would not have been aware of their own strengths. It was an incredible lesson on the value of the personal and individual.

On a personal level, Donovan's reality of day-to-day living impacted us, his wider family, and indeed sometimes the community. On a few occasions that impact was memorable. One such example was when Conal McFeely, Development Executive of Creggan Enterprises (a social enterprise based at the Ráth Mór Centre in Derry's Creggan area), became concerned over wheelchair access in various buildings there. The architects and builders were of the opinion that access was satisfactory. But to assure himself, Conal invited Donovan to travel through the premises in his wheelchair. This exercise revealed access was restricted and steps were subsequently taken to remedy the situation.

On another occasion, Donovan was invited by the Head of the Community Occupational Therapy Department, Paraig O'Brien, to help him demonstrate different housing standards by making a short video. Paraig was very supportive of our work throughout the years and always had a clear user focus in his own work. This video demonstrated more than any academic paper the reality of different space provisions in housing standards. The video helped to impact housing policy. Just two examples of the power of the individual.

FINDING A VOICE – THE STORY OF THE FAMILY INFORMATION GROUP

In the Family Information Group we often claimed we were coming from the perspective of experience and wanted to share this with others on an equal basis. This resulted in the development of a concept that we called ‘parents as professionals and professionals together’.

For many, ‘parents as professionals and professionals together’ was not an easy concept. Nonetheless it was a viewpoint that the Family Information Group promoted and firmly believed in. We genuinely saw parents as professionals caring for their disabled child or children, and their other children. They had acquired specific skills and knowledge which in other circles could be deemed professional which put them on a par with those consultants and other health experts who worked with us and our children. As professionals together, it was hoped in some small way that the quality of life would be improved and that we could work constructively on what we had in common, rather than what we saw as our differences. This would have been positive professionalism for all.

When a bottom-up approach to user involvement is mentioned, this is what we understood by it. We were at the bottom, the marginalised. We were on the ground, experiencing life as it was for us. Our issues, our knowledge, our experiences were coming from real life and not from theories or concepts and we certainly did not convey a sense of vulnerability that is often associated with marginalised groups.

Initially, many of us were unsure of our own expertise and knowledge until we got together. In fact, this was the basis of our capacity building – the recognition of our own expertise and knowledge. As we began to identify and raise our own issues from our own perspective, in hindsight we realised that this is what is often called ‘community development’ although in those early days such concepts were very far from our focus.

The power of this shared experience should not be underestimated and through this understanding we gradually became empowered; we began to take back control of our lives, control which had been seriously undermined with the impact of diagnosis. When parents

were in a position to meet and discuss with professionals working in health, social care, housing and the voluntary sector through a series of ‘Professionals Together’ events that we organised their confidence in their own ability and knowledge grew. This is reflected in the comment from Harry Marsh, former director of Contact a Family:

‘... it can be rather painful for some parent carers to see academia, government and national charities slowly catch on to the messages they have been crying from the rooftops for many years.’

Our core concept – the ‘family view of disability’ – was simply that, the view of disability as seen by parents and their families. Over time we developed this concept further as a training tool and it was used in awareness sessions to outline the general road most parents travelled and the issues they faced. It was encouraging to watch the development of the parents’ voice as they gained confidence through knowledge, information and experience and were able to contribute so ably at conferences and workshops not just facilitated by our group but by others, too.

We came to believe that any parent, with the appropriate support, could voice their issues and perspective in an effective way without any systematic training. There are some who would disagree with this but I am confident that although training can be helpful, it is not always necessary.

No-one came with a magic wand to give us power, we were empowered from within by recognising our own strengths and abilities and through identifying these with the experience and knowledge of others. For a number of years these strengths and abilities had been hidden, masked or impacted upon by the excessive caring demands placed on us through caring for a disabled child and any other children we had and balancing that care.

We deliberately wanted to move away from the role adopted by some other support groups where the emotional sharing of experiences was the basis of mutual support. This type of support was, and is, beneficial to many participants. In our case we wanted to

learn practical skills from each other's experiences and see how we could move forward – but on a more rational, rather than emotional, level. Emotion was sometimes still part of what we were doing but it was not the main focus.

Later, as we designed courses for parents ourselves and with others, we included areas such as information provision, getting to know services, finding out who does what and how to work through the system. Over the years we brought out several information books which we widely distributed, providing guidance and information for parents, families and those working with families.

We never moved away from our core aim that those who use services should be involved in the planning and delivery of those services. We were more an advocacy than a service delivery group, which sometimes became a problem when seeking to secure funding.

As we grew individually and collectively in our knowledge and experience we realised at times we could not do things alone and had to work in partnership. In the context of user involvement, we consciously tried to work with statutory and other voluntary agencies, developing an understanding of roles and seeking to influence both service delivery and design. At that time this was quite radical, in an era when user involvement was more whispered than shouted about.

The relatively small Family Information Group, seen by many as hard to reach or marginalised, became part of mainstream activities through participation in a range of networks.

We were engaged in some key partnerships such as Children's Services Planning, Regional Child Register, Regional Hospital Inspection, the Department of Health, Social Services and Public Safety (DHSSPS) consultation on disability issues, the development of a Healthy Living Centre in Creggan, Early Years, an Inclusive Play Park (Liberty Consortium) and Altnagelvin Hospital User Forum. Through these partnerships we developed and grew and appreciated more deeply our own expertise and knowledge as well as that of others from quite different backgrounds. Our aim was that through these partnerships we would enhance the quality of life for our disabled children, their siblings and our families and create with others a more sensitive patient-focused service delivery. We were not interested in merely taking part in talking shops.

Through partnerships, publicity, information provision, awareness raising, workshops, conferences, training, campaigning and publications, we developed our work. The individual experience of the parent was always central to this. Emotion and feelings were integral to that experience, and though these were always present, through time we learned to channel them into a more objective and challenging approach to presentations.

Frequently we were invited to share our knowledge and experience, including with social work students in the two NI universities. Huw Griffiths in the Magee Campus of Ulster University, Gerry Skelton at Belfast Metropolitan College and Joe Duffy at Queen's University and their colleagues were instrumental in supporting and encouraging me in this work which continues on an occasional basis today.

It would be unrealistic to paint a rosy picture that all these processes were simple and straightforward. It was challenging work at a time when discussion and understanding of user involvement were in their infancy. There was often much soul-searching and compromise that became a way of life as healthy relationships developed. Positive relationships followed, particularly with staff in the former Foyle Health and Social Services Trust and the Western Health and Social Care Board, staff such as Tom Haverty, Martin McCafferty, Gerry Conway, Siobhan Livingstone, Dominic Burke, Stella Burnside, Elaine Way and Noel Quigley. We also worked with a number of excellent and supportive voluntary groups, particularly in the Creggan area, but also in other areas of the community.

At a regional level my own involvement as a member of NISCC gave me further opportunities to explore user involvement. For eight years as a lay Council member I benefited from working with people from different backgrounds as we began the task of regulating the social care workforce and in particular the social work profession. Jeremy Harbison, chair of the NISCC, was very supportive and very encouraging both inside the Council and in the wider community.

There are many stories that could be told of our group. Our greatest testimony was our significant contribution to the housing campaign called 'Homes Fit For Children'. We, with others, attempted to eradicate the means test associated with the Disabled Facilities Grant.

What at first appeared a very private concern became one of our most public issues and it featured widely in the media.

This transition from personal to public was manifest in the work of our group and none more so as it came towards our final days. What started as a very introvert look at our own personal and individual disability issues and how they impacted us, gradually moved towards more general issues that also impacted a wide range of diverse individuals and groups.

Our final book, *The Way I See It*, was published in 2008 and it was to have a memorable impact. It contained a collection of diverse views on user involvement and came out shortly before the group closed down in the spring of that year. The subtitle was *Personal Views on User Involvement, Partnership Working, Inclusion and Real Life* which is what it is about. What I think is even more noteworthy is that the contributions came from a range of people including parents of disabled children writing for the first time and it has to be emphasised that these contributions were in their own words. But with no further funding secured, the Family Information Group went out of business.

There is one niggling question that remains: Why did we fold? There has been much debate and discussion about this but still no clarity. Were we just too challenging? Were people frightened of our advocacy role and felt at times that we were biting off the hand that fed us. Or is this just an irrational conspiracy theory?

Another quite different question is: How did a group – initially set up to develop a time-limited project (possibly one or two years) – survive for ten years?

I remember shortly after our group first received funding going to meet a senior member of the board to ensure they were clear about our group's role. He affirmed advocacy was a priority in the board's funding policy which was why they were supporting us. It was very reassuring – at the time. Unfortunately, this reassurance did not last and several years later funding ceased. Perhaps the new focused targeting on specific projects prevented any leeway to fund us. Or maybe it was just that advocacy was no longer a priority. Whatever the reason, it was clear there would be no further financial support

for our work in the community. It was a devastating blow after over ten years work and there was no chink of hope, it was over.

Although we campaigned against the closure through the media, and protests gathered a considerable amount of support, it was over and we had to accept it. There is no doubt that we raised the profile of parents and families of disabled children and we put a marker down that the expertise of such parents and families, as articulated by them, is critical in partnership working.

Our imminent closure in 2008 did provide us with a really positive appreciation of our role in the community. Individuals and groups expressed support and identified how we had contributed so positively to them, our community and partnership working. Parents, friends and supporters stood with professionals from statutory agencies in a public protest over the threat to our work. We were going out with a bang not a whimper.

As it became clear we would no longer survive in our role, we did discuss the possibility of changing to a more service delivery type of group, in other words offering practical services rather than campaigning. We knew this would have perhaps allowed us to continue in a different role and maybe even opened up potential funding opportunities. We also knew we would then have to compete with several excellent organisations already doing this type of work, most of whom we had worked in partnership with.

Unanimously we rejected this idea, not out of stubbornness, but out of integrity to our own initial core values. We were parents of disabled children speaking on, and highlighting, the issues impacting our families. If the housing issue was the positive example of partnership working, the inability to secure funding must be the negative one.

In May 2008 we officially closed our doors.

It is ironic, however, that even today the issues highlighted by our group are still raised by some people. It is also ironic that a lot of the work carried out by us and others working in partnership are very similar to PPI and user involvement, albeit from a different starting point.

But what is neither strange nor ironic is that there will always be a need for independent groups and individuals who are not afraid

to advocate, to challenge, to pursue real engagement, partnership working or user involvement. User involvement is not an option; it is a necessity.

Our story has been about the development of skills, the importance of the user experience, a willingness to engage, mutual respect and values associated with such involvement. It was about finding our own voice and expressing that voice in a way that we chose. As parents, we were not trying to minimise the stresses and strains of our role in life, but we did try and move away from the platitudes and dependency attitudes prevalent in certain circles, including some of the media.

Although in pressured moments we may have felt ‘poor me’, that was not the way we wanted to be portrayed in public. At that time we were unaware of the full impact of what we were doing and we were so preoccupied with our personal lives that it only gradually hit us that we were beginning to take control, to be responsible for our issues and this was our choice. Through that voice we began to realise that we were not alone, that we shared a common interest with many others.

Although the development of user involvement and partnership working were central to the group’s own development, they were not pursued in themselves. We did not wake up one day and declare we must work in partnership today or maybe we will try user involvement. It was through user involvement and partnership working that we tried to address the issues and concerns that faced us.

There is a subtle difference. Just as we valued and acknowledged our own expertise and knowledge, so, also – when it was appropriate – did we value the experience and knowledge of others.

User involvement and partnership working became embedded in our culture, they were part and parcel of the way we worked. We saw both the potential and actual benefits of this way of working and these far outweighed any associated problems or challenges.

We worked on the issues around disability with others and over time both user involvement and partnership working emerged. This took time of course, but it did happen. We learned through action, not debate and discussion on theories and strategies.

Through time we realised that we were not unique in this wider area of involvement. As we worked in partnership with individuals and groups (both statutory and voluntary), the principles and values that they held dear with regard to engagement and involvement helped to challenge our own understanding of such concepts. Despite differences at times, healthy positive working practices emerged as a result of dedication and commitment.

But more importantly than that, we discovered through all of those years of commitment and endeavour that user involvement works, that it does make a difference. At the beginning, as individual parents, we did not know that we could sometimes change things. This is the key message of our work and once that is understood it would appear that anything is possible. Hopefully this is our legacy.

It is not easy at times to share your life's experiences with others in a public arena. Often it seems as if you are complaining, even though you are not. In reality, you are actually raising issues. But even though most of us value our own privacy, there are times when going public may be the only way we feel we can address those issues that need to be dealt with.

This emphasis on issues rather than the individual experience changes the personal into the public and into the whole area of wider involvement. What we term issues are the daily lives and experiences of people dealing with major health-related conditions and social care situations, and many of them often do not realise that others are in the same situation as themselves. Unless you are in that situation, you may never have any idea of the pressures on patients and users, and often these pressures can prevent users and patients from seeing the bigger picture.

In certain circles there can be much discussion and interpretation of issues. It is often frustrating for users to hear their real-life experiences talked about so uncaringly by some people who have little, if any, knowledge of such issues.

The thrust of the Family Information Group was to facilitate the voice of parents and their families in identifying their own issues and concerns. It is significant that in the early years of our project we could identify the appropriateness of partnership working, long

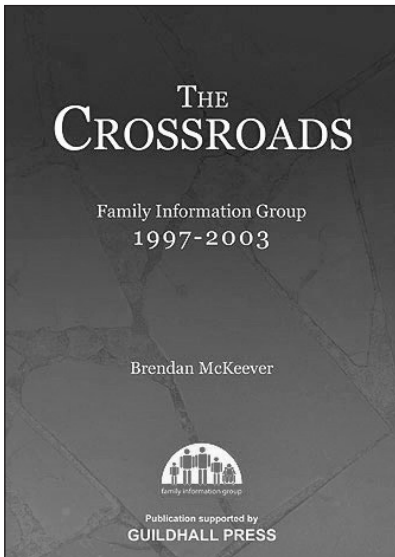
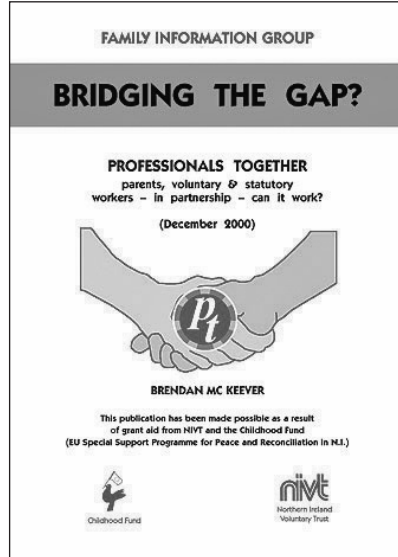
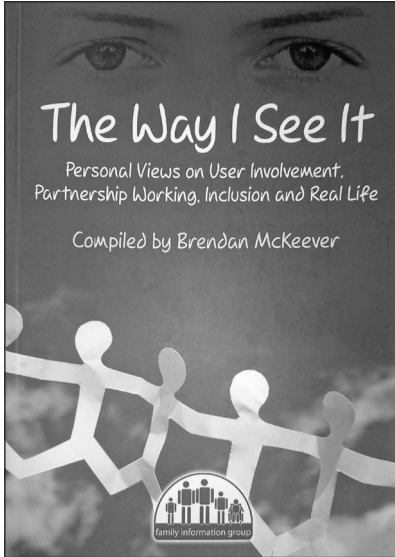
before involvement became a mainstream topic for discussion.

Somehow, families of disabled children (including disabled children and their siblings) have to find a voice and have a significant say in the planning and provision of services. But just as importantly, those who plan and provide services must be willing to listen and to act and work with those who use services.

Similarly, other user groups should be facilitated to find their own voice, too. Our work in the Family Information Group focused on our issues; through that work we learned that there are many other groups and organisations that have been for many years highlighting their own particular concerns and issues.

The individual and the public voice are complementary, not in competition, and each can enrich the other. Every individual does not have to enter the public arena; nor does the public field necessitate that you forego that personal private experience. Users should make their own choice as to what role or roles they want for themselves, they should not be forced into options they are not happy with.

Family Information Group Publications
 PDF versions of some of these publications can be
 accessed at www.ghpress.com/figbooks



family information group
Winter 2001

Brendan McKeever
Family Information Group

Huw Griffiths
University of Ulster

IN THE TELLING

Research into the experiences of parents recalling how their children were diagnosed with disabling conditions

Childhood Fund

This publication has been made possible as a result of grant aid from the Childhood Fund (EU Social Support Programme for Peace and Reconciliation in NI)

The Handbook 2002

A Handbook for parents of children with physical and/or sensory disabilities and those who work with them.

This publication has been made possible with financial assistance from the DSD under European Peace II funding. compiled by Brendan Mc Keever

DSD
Department for Social Development

THE IMPOSSIBLE
TOOK A LITTLE LONGER

Brendan McKeever
Family Information Group

listening to parents

parents as professionals

Brendan Mc Keever
30th June 2000

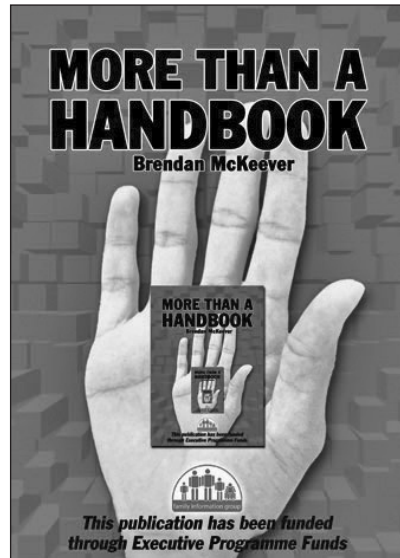
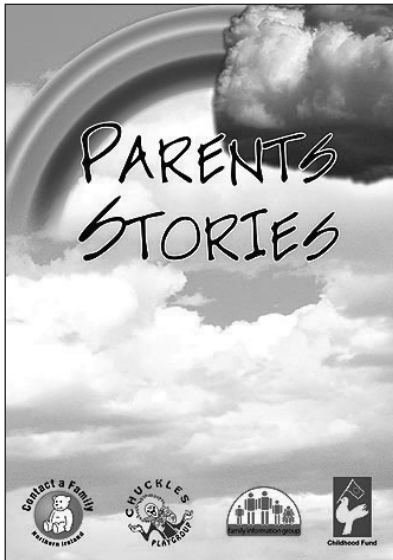
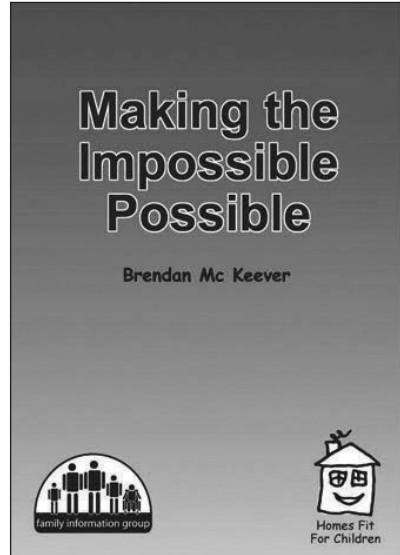
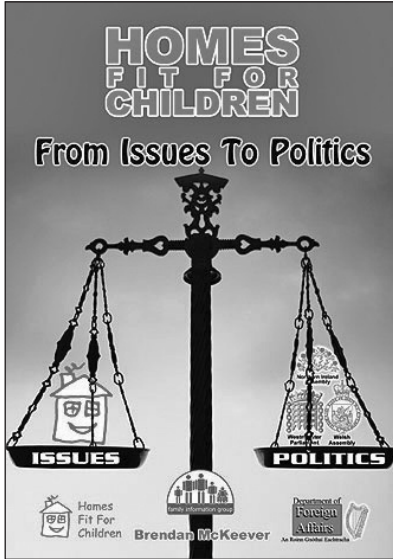
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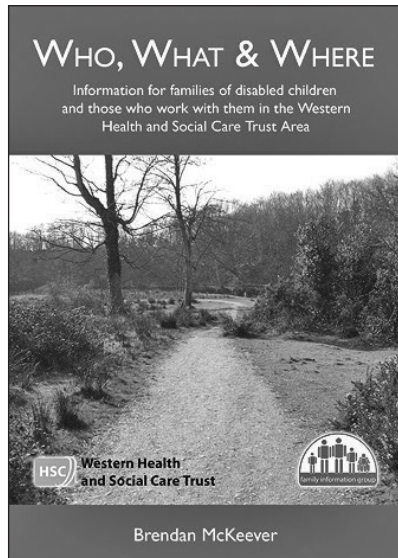
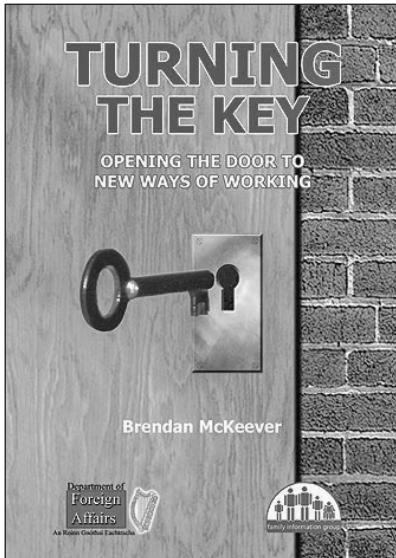
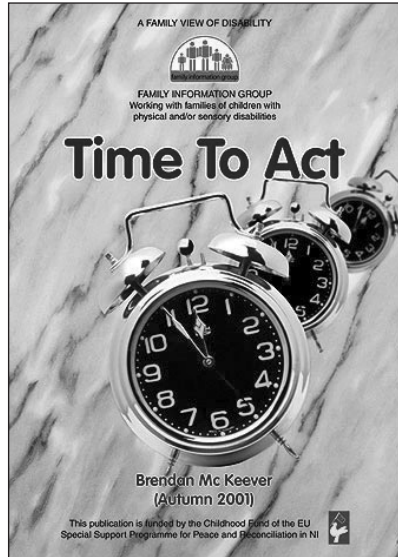
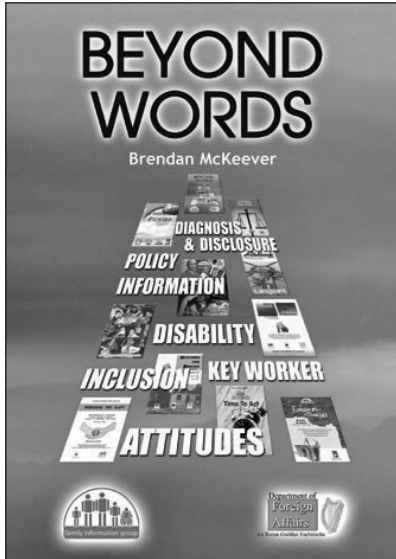
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FAMILY INFORMATION GROUP





PARTNERSHIP WORKING – HOMES FIT FOR CHILDREN

Partnership working is key to the development of user involvement. There are many excellent examples of good practice in partnership working from which we can all learn.

The campaign to improve private housing conditions for disabled children and their families – ‘Homes Fit For Children’ – is one such example of which I have personal knowledge as the Family Information Group had a part to play in this. For those who have no direct knowledge of housing and disability issues, and maybe even those who do, this can be a very complicated issue. To try and simplify things, what this campaign was about was to get rid of the means test associated with the grant available to assist families to adapt their home.

The means test was an assessment of, in this case, the parents’ income to gauge if they should contribute towards the grant, pay nothing at all or indeed be excluded from accessing the grant. The specific grant to assist in housing adaptations is called the Disabled Facilities Grant. In Northern Ireland the grant is administered by the Northern Ireland Housing Executive and the assessment of whether adaptations were needed was carried out by an occupational therapist from the local Health Trust.

The policy of means testing had resulted in some parents not being able to afford adaptations. Some simply went into debt to furnish the appropriate adaptations while others continued to live in unsuitable accommodation. The means test associated with this grant was later discovered by campaigners to be unfair, particularly as it did not incorporate the actual expenditure of the family but instead used standard fixed allowances for key outgoings which had no relation to real family outgoings.

The campaign, founded in England in 1997, lobbied and raised awareness of the issues. Two years into the campaign it was felt that it would go nowhere unless parents were also engaged. It was believed that the experience of those most affected by this policy needed to be incorporated fully in what was happening.

The involvement of users was seen as a natural evolution, not a vague concept but something that was necessary for the campaign.

The users themselves also knew why they were there – to help make a change, to make the campaign real. There was absolutely no sense of tokenism.

Plans were put in place to engage politicians at local, regional and national level and publicity was carefully designed to ensure sensitivity to parents and disabled children at all times and to correct any misinformation that may arise. The spreading of information was central to the campaign and the parents' experiences were integral to this. The campaign had moved into the political arena, at that time an unfamiliar place to many parents.

Researchers were collating information. Occupational therapists were gathering data on the impact of the current policy. Those involved in statutory services, including housing officials, were confirming the findings coming from researchers, occupational therapists and those working in the voluntary sector, identifying that current policy was having a negative impact on parents.

At the outset in Northern Ireland, where it had been decided to concentrate and focus the campaign, it was local voluntary organisations which identified change could happen. In hindsight, it emerged that many marginalised organisations in the voluntary sector supported the campaign, even though they had no association with disability, primarily because they identified closely with issues impacting families of disabled children as marginalised issues.

Resources were minimal, with just enough to fund expenses and the publicity surrounding the campaign. There were no extravagances. Communication, particularly the use of accessible information, was critical to this campaign and everyone involved was kept in the loop. Email was essential in this. By raising awareness of the issues through publications, leaflets and the media – and by highlighting the personal experience of parents and their families of the impact of this policy of means testing – the campaign made significant progress. The involvement of the voluntary and community sector, supported by a wide range of politicians, and the evidence brought forward by occupational therapists and housing officials sealed the fate of the means test.

On 16 February 2004, the means test was abolished in Northern Ireland. The announcement was greeted with disbelief; seldom did

Northern Ireland lead on policy change. It is a real testimony to the power of partnership working that this momentous achievement was realised. No ifs, no buts, no compromises – the means test was abolished.

But the story was not over. What about England and Wales? (Scotland had a different system at that time.)

On 30 September 2005, over 19 months on from the abolition in Northern Ireland, Wales abolished the means test. On 30 December 2005, England followed suit. Over eight years after the campaign was initiated, outcomes that once seemed beyond expectation had come to fruition.

Life had changed for families of disabled children, and families of disabled children were a vital part in making that change. User involvement had become more than an abstract theory, it was real and it worked. Families of disabled children, as a result of this campaign, could now have easier access to the grant that would enhance the quality of life for their disabled child, their other children and the whole family.

But for those involved or indeed impacted by this campaign, what did it mean for them? Following is a selection of comments that were received after the campaign. They speak volumes, much more than theories, processes or action plans as to what this all meant.

‘This is great news and is the result of a concerted effort of a great many people.’ (Valentina, parent)

‘This is due, I am sure in no small way, to all your personal and professional efforts for and on behalf of families everywhere in the UK.’ (Athena, voluntary sector)

‘You must be delighted that all your hard work has paid off! Never underestimate ... and all that! Well done.’ (Alison, voluntary sector)

‘I think Parent Power is going to come of age in the next few years. Keep up the good work.’ (Brid, Health Trust manager)

‘Without your efforts, John Prescott would have held out and we would have got nowhere.’ (Philippa, occupational therapist)

‘I have so many families waiting for this news. You were able to say things that as professionals we could not.’ (Alison, occupational therapist)

‘It will make such a difference to the lives of so many families.’ (Pat, occupational therapist)

‘What a result. You and your team should be very proud of all your efforts and perhaps “bloody-mindedness” in achieving such a result.’ (Gary, Mel and Sophie, family of a disabled child)

‘You have achieved so much and I know our children and grandchildren will be so much better for it.’ (Maggie, parent of a disabled child)

‘It’s a marvellous result that will benefit the lives of so many families. It is through the dedication, tenacity and leadership of people like yourselves that such injustices are successfully resolved.’ (Stuart, Linda and Ashby, family of a disabled child)

‘It will make a huge difference to us and many other families.’ (Ian and Susan, parents)

‘So, almost two years on (from the Northern Ireland decision) the seemingly impossible has been achieved.’ (Bryony, researcher)

‘Congratulations. I can certainly see many hundreds of families of disabled children benefiting from this in the years to come.’ (David, NI Housing Executive)

‘Hopefully this will be an early Christmas present for some parents. It is great to know that we can make a difference no matter how small the contribution.’ (Anne, parent)

‘Really pleased. Well done to everyone.’ (Roger, English MP)

BARRIERS TO USER INVOLVEMENT

Below are listed very real barriers or issues which can discourage or prevent user involvement, alongside potential positive responses. Some of these have practical implications but others require a change in attitude, culture or approach.

Attitudes (Negative) – It would be good practice to try and determine the source of any negative attitudes and to find out if they can be addressed and turned into something positive. There should be no judgements made because those concerned may believe they have very valid reasons for holding certain attitudes.

Bureaucracy – As in a number of other areas, often the overuse of paperwork can cause serious problems for those wishing to engage, particularly for those who are not used to lengthy form filling. Some degree of administration is always necessary but to nurture the involvement process, this should be minimised where possible. This does not mean we should lessen accountability; rather we can look at accountability in a more creative way.

One specific area where bureaucracy can create real difficulties is in the process and timing of payments to users which is frustrating for them. There are many examples of where good practice has resolved issues around this from which we can learn.

Just because we were overwhelmed by bureaucracy in the past does not mean it has to be the same in the future. Involvement often entails change to the way things have historically been done, even when there is resistance to that change which can create problems.

Culture – This deals with practices and beliefs which build up over a period of time resulting in ways of doing things which become the norm and are seldom questioned or challenged. This culture can be based on a belief that what has worked in the past should not be changed and so antagonism and reluctance to change builds up and anything new is treated with suspicion. But involvement may require a cultural change, an ability to appreciate knowledge and expertise as coming from different sources, including users.

Disempowerment – There are often disputes and disagreements over power and the power base on which involvement is founded. This leads to the misconception that someone can empower someone else, misconception because in positive involvement there should be an equal power base, no-one should control anyone else. However, sensitive facilitation and support can help empowerment to develop. Often capacity building exercises can also be used to help.

Disrespect – It is almost impossible to develop any kind of relationship where there is no mutual respect. There must be a commitment to respect each other (individuals and/or organisations) and an ability to try and understand the other's point of view, even though this does not necessarily imply agreement.

From the beginning, an appreciation of the importance of respect is essential. It has often been identified in research as one of the key issues that can be vital in encouraging involvement and when missing can undermine such involvement.

Exclusion – It is often claimed that only well-known and respected organisations are invited to engage, as if from some exclusive list. To ensure inclusion, extra efforts need to be made to engage the most hard to reach and marginalised groups and individuals. Although there are challenges to including those who are so often left out, they also have a right to be heard.

Insensitivity – So many professional relationships and engagement processes break down because insensitivity is shown by one side or the other. Sensitivity, however, requires acknowledgement of expertise; it involves all the issues around respect already mentioned but at its most basic level it means having good manners.

Linked closely to sensitivity is empathy. These very human emotions should always be conveyed because without them there will be difficulties in relation to real engagement.

Lack of Communication – The lifeblood of involvement is based on how we communicate with each other, so it follows that when there is

a lack of communication often involvement projects fail. How, when, where, with whom, what, why and in what form we communicate all need to be considered if we are to try and address the communication issue. If we want people to understand what we are talking or writing about then we should use Plain English and avoid jargon, acronyms, technical language, buzzwords etc. We should also be as brief as possible and avoid long verbose reports.

Lack of Appropriate Training – Sometimes it can be helpful if people receive training to develop their capacity to engage whether as a user, staff member or manager. Staff and managers may require more awareness training of the user perspective, and at least some training should be delivered by users themselves.

Users also may need training to help them be more familiar with health and social care agencies and their structures, policies and ways of working. But their life experiences may have enhanced other skills and knowledge they already have.

From time to time there may be need for training on specific issues so that all those involved will have an understanding of these issues, preferably before they arise. On other occasions training may not be appropriate at all and this, too, should be recognised.

Lack of Outcomes – It is very frustrating to be involved in a process which eventually leads to nothing, particularly if promises were made at the start. In the user involvement process, those participating may be able to handle outcomes which are different from what they expected but it becomes increasingly difficult to remain engaged if no outcomes at all are ever achieved. To sustain involvement, there has to be evidence that it is working.

Prejudice/Discrimination – People come to involvement from different perspectives and sometimes they hold prejudices and can discriminate against others. There are those who firmly believe that those who use services should have no say in those services at all. Also there are those who just as firmly believe that all those who provide services are the same and are not capable or knowledgeable enough

to design and plan services. When minds are blocked by prejudice and/or discrimination, it is very difficult to make any positive inroads.

Lack of Resources – Adequate resources need to be allocated to maximise the benefits of the user involvement process.

USER INVOLVEMENT IN THE NI HIGHER EDUCATION SECTOR

This section highlights how user involvement has developed and grown in social work studies in Queen's University, Ulster University (Magee Campus) and Belfast Metropolitan College. Over the years I have been involved in both universities and the college on various aspects of user involvement and have learned a lot, not just about involvement issues, but staff support and the shared experience and knowledge of the other users who contribute to higher education.

For some time, the value of the input from users has been acknowledged in social work studies, as well as the wider health and social care field. Specific benefits and claims have been made about such involvement such as: strengthening communities, increasing citizenship and promoting social inclusion, improving the design and delivery of services, ensuring that services better meet the needs of those who use them and making social work education more meaningful for service users, students and educators.

The term user involvement has different meanings and understandings, just as the terminology used to describe those involved such as users, service users, carers, victims, survivors, clients, citizens etc. There are no objectively identified rights and wrongs in the use of terminology. The most practical advice is to listen to the terms used by those directly impacted by user involvement first before deciding what is appropriate.

From its inauguration in 2001 the NISCC had a very strong user ethos and this is reflected in their code of practice which all social work students and qualified social workers must sign up to.

With such extensive strategic planning, the question needs to be asked: What do users bring to social work education and training? This is very much open to interpretation. However, as social work is seen very much as a 'caring' profession, some would argue that skills around sensitivity, empathy, understanding and emotional awareness are all enhanced by engaging users. However, important as these are, it is acknowledged that what is unique and even more important through these inputs is the reality, the real-life experience that users bring to social work itself.

In the past, anecdotal evidence has indicated that generally user involvement in social work education, although challenging, has been a positive experience for both students and users. More recently a systematic approach to evaluation is being looked at by both universities and models of evaluation are being developed to capture both the student and user experience. Eventually we should have more empirical evidence to gauge the effectiveness or otherwise of such involvement.

Meanwhile it often seems to be forgotten that user involvement is a developmental process that has progressed over time. It has not stood still. It is equally true that user involvement is an option that only a few may take up. But for those who choose to be involved it is primarily about having a voice, a voice that possibly can create change.

It must also be emphasised that not only is involvement a choice users can make for themselves, but that they can have degrees of engagement, from very little to total involvement. But much more than this, users, lecturers and staff have built up a partnership approach to such involvement on the basis of mutual respect and trust, even when risk is involved. Particularly in the early days, university authorities had concerns over the welfare of users who became involved in social work education. They were worried that reliving experiences as part of their teaching could have a negative impact on them.

There are always concerns over risk and tokenism from those who have been supportive of user involvement and this is understandable. But sometimes such sentiments from outside observers can be seen as placing barriers to real involvement. From a user perspective – looking out from the inside – although there may be a possibility of risk and tokenism, years of work, experience and development have lessened this possibility.

Initially, most users in the early days were invited as ‘guest speakers’ to ‘tell their story’ to students studying social work. Some of the users would have been known in the community, others would have been personally known to lecturers or their colleagues at the universities or colleges. For many at first this was what user involvement was, an occasional input to social work education.

As user involvement became a key function of a few lecturers (often in addition to their existing workloads) and as a particular emphasis on such involvement became a significant policy requirement of NISCC, so, too, did supporting users through a partnership approach, where users were being seen as active participants, rather than as guest speakers or the focus of research. Partnership working has been part of social work itself for a number of years.

At first these were occasional invites and concentrated mainly on whatever expertise users were bringing. Very few users knew the background or full context of social work studies or social research. The reliance was primarily on emotional engagement. A short meeting with the tutor or researcher in advance was more than enough for the user who was usually known to the tutor or researcher beforehand.

The emphasis primarily was on students being exposed to real-life experiences in a controlled educational environment before they actually went out into the world to apply what they had learned. This was the understanding of those involved in delivering the courses, those users who were making inputs and the students themselves.

Students studying for professions must prepare themselves for whatever discipline they intend to work in. In the past in some jobs this was through apprenticeships, on-the-job training or through trainee positions. Trainee positions have been done away with and no new trainees for statutory health and social care agencies are being recruited.

With the development of professional qualifications and the emphasis of study at graduate and post-graduate levels, opportunities of direct experience with users often come within the confines of university life first. This can be seen in the medical field just as much as with social care studies where patients have a significant role in educating some of the medical professionals.

As the emphasis on user involvement in universities and colleges grew in Northern Ireland so did the number of users required for input. What was once an occasional input by a few became a growing trend of more regular inputs by a significant number of users. Also the expertise and knowledge of some tutors grew as partnership working with users offered new challenges and opportunities.

Although the emphasis was still on students gaining first-hand experience and knowledge through user input, there was a growing trend to systematically support users involved in this process, not in a benevolent or patronising way but in a spirit of true partnership, where all involved benefited.

In the universities and colleges, it became common practice that tutors would meet users in advance of any planned input. These meetings afforded the opportunity for users to voice any concerns, worries or issues or share some ideas. Also, significantly, time was given to outline where the proposed input linked to specific social work themes or issues so users would have a context for 'their story'. If needed, the tutor would offer assistance with this context.

Practicalities, and these are very important, were also sorted out – venue, parking, payment, amount of time, arrangements to meet on the day etc. Usually there would be an undertaking that the tutor would also be there on the day to offer support, if needed, and to answer any additional questions.

A 'contract' would be drawn up with the students – what could be asked, respect to be shown to the user (no mobile phones or idle chat) and students would be given a brief overview of the user's proposed input.

The users, students and staff would agree that potential oppressive practice would not be tolerated in language or action and that policy and legislative requirements (such as Equality, Disability and Anti-Discrimination) would be adhered to. Any networks of support that were available to the user would be identified, particularly if they came from an organisation where a named person would be the support link, if needed. Individuals, not linked to organisations, would be made aware that the tutor or lecturer who engaged them would be the support link if required.

Seldom, in my experience, has a user been plucked directly out of a community and put in front of a student audience. But sometimes this may be the perception of some of those not directly involved in this process. Another more common perception is to view users as vulnerable and weak in themselves rather than in the context of the situation they find themselves in. The concern is that such

perceptions can prevent us from acknowledging the strength and expertise of users and may influence us to become preoccupied with ideas of protection and limitation. Certainly there can be risks, user involvement is about taking risks. But these can be managed. Some are wary in the belief that the involvement of users has the potential to fail. But this could be said of any innovative approach to learning and education.

There is a possibility that the emotions associated with being a user, if articulated by the user in their work with students, could have an adverse impact on students who have had similar experiences. For example, someone giving a talk on domestic violence would not know if any of the students had suffered similarly, and their talk may open emotions that could negatively impact a student.

Concerns over the personal impact on the user of reliving life experiences, of triggering painful memories, of responding to sensitive questions from students are well founded. But these concerns can be alleviated by the support already outlined – from tutors/lecturers, support groups, the existing knowledge and experience of users and the undeniable fact that users choose what they will input themselves.

With the encouragement and support of the key lecturers involved in user involvement, users have become involved in a variety of committees in university institutions. They have taken on roles as ‘user researchers’ engaging with marginalised groups, they have participated directly in research, action research, E-learning, work on accessible language and information, and currently in what is called ‘Preparation for Practice’. This is not exclusive to users in Northern Ireland, nor indeed just in universities.

For those studying social work at undergraduate level, Preparation for Practice means something very specific. At a certain time in their studies, and before they actually go out into placements, students must demonstrate the skills they have learned and the knowledge they have gained in a role-play situation. If they are unable to meet the criteria set out for this exercise, they cannot go out on placement and indeed they may be asked to leave the course.

Students must also rehearse interviews based on constructed case studies. Most of these interviews take place between fellow

students but sometimes actors can be brought in. Several years ago users were invited to participate. Some were agreeable to use their own stories, but a few stated they preferred not to so initially acted out constructed case studies. In 2009, the Magee Campus of Ulster University incorporated real stories as did Queen's University the following year.

I have been involved with both universities in these interviews. There are other practice interviews as already mentioned where students perfect their skills with each other or actors. Also in Queen's University, as part of the assessment of students, users and carers act out their own case studies and contribute to these assessments.

On a practical level the involvement of users brings what I would term the 'unknown' into the interview. Students just do not know what to expect, they do not know what the user will say. In their mock practice with fellow students, students would state that so often these are predictable. But interviews based on real-life situations are unpredictable.

Prior to these real-life interviews, students generally are uptight and nervous. Part of this has to do with the unknown. But also they appreciate that it is vital they get these interviews right so when they are eventually assessed they meet the criteria set out. However, sometimes students are apprehensive because they do not want to offend users or ask probing questions.

After the interviews most students will articulate that they feel the interviews were helpful and that the true story made the interview more real and this contributed to the learning. Although evidence from students and users indicates the effectiveness of these scenarios, an enhanced systematic approach to gathering additional information is required in the universities and further education college to achieve a more accurate analysis of feedback.

The introduction of users into Preparation for Practice interviews with their own case histories was innovative. As with any new venture there was an element of risk, the main one being – will this work? Although those directly involved with users at the universities were very supportive and encouraging, the process of engaging at this level took time.

Whether real or perception, initially there seemed to be at one level a resistance – or at least a gentle reluctance – among university authorities to move forward and there is a possibility that this was based on ethical reasons or the possibility that some people were overprotective of users. Whatever the reasons, such reluctance was not present among the staff working on the ground.

For university and college staff engaged with user involvement issues, the welfare of users has always been paramount. There has always been a delicate balance between risk and involvement but this has been a calculated risk. It is perfectly understandable that a project such as this will take time to establish as university authorities examine all the possible angles. As outlined earlier, support mechanisms had already been built into user involvement at universities and colleges of further education by tutors and lecturers to help minimise risk. At Queen's several of those involved had also participated in a specifically designed User and Carer course.

It has to be acknowledged that it was only through the perseverance of lecturers in the universities and college that this level of user involvement became possible. It was they who had to provide the evidence and assurance that this project would work and there were many meetings at the highest level to facilitate this. In the end their efforts paid off and Preparation for Practice interview skills incorporated real-life user experiences.

Projects I have been involved with at the universities include consultation work on online student resources, an action research exercise with post-graduate staff, an international DVD on the user experience, follow-up research on students' experience of user involvement, co-writing an academic paper and drawing up a strategic plan to engage users. None of these would have been possible without trust and respect facilitating empowerment. There are other users who have taken on specialist tasks and some users have gone on to study at university level including the degree in Social Work.

Users know exactly what they are doing and why they are doing it. The key university staff involved in user involvement ensure that users connected to them are not exploited and they would not attempt to engage users in activities which could in any way harm them.

There are still some who challenge the merits of engaging users in social work education. This may emanate from a culture which views the experience of users as being irrelevant in this field. Or it may be due to a concern for the user and a fear of exploitation or tokenism.

The only way to redress these concerns is by listening to the users involved and providing evidence from users and staff as to the merits of such involvement. If there is not a recognition of the value of the user experience, then it will be difficult to challenge the negative perception that user experience is not relevant or beneficial to user involvement at all levels.

Often in this context there is a debate over power. Power has often to do with informed choice and it is users who choose to engage in this process. Also it is about identifying barriers and then going on to address these barriers. Users choose which particular part of their lives to share; they write or co-write (with support) their case study. Most will already have shared this with students in lectures and seminars. They will prepare in advance with university staff prior to the interview. They will meet the students briefly first.

This exercise is the closest I have ever got to user involvement with social work students and I feel that this process not only adds value to my work as an educator and a teacher but also expands my own learning experience. I feel confident and secure through my life experience but also through the support of the tutor. Some may call this empowerment.

The development of user involvement in such settings has not been in a vacuum. Users themselves have developed and grown through the sensitive support they have been given and, together with students and academic staff, learned the true meaning of partnership working with some even having gone on to further education as a direct result.

POINTING A WAY – THE TORCH

The letters that make up the word ‘torch’ hold the key to understanding at different levels what is needed to ensure that user involvement can work. They refer to, and are a handy reminder of, the values and principles that underpin user involvement and which are so critical to its development. Below is a summary of the key elements that shape user involvement.

Values

- T** Trust – this is essential, mutual trust and addressing mistrust.
- O** Openness – often called transparency, this is needed so that everyone knows what is going on.
- R** Respect – valuing everyone involved.
- C** Commitment – this and perseverance will ensure that user involvement will last.
- H** Honesty – an essential quality and value.

Principles

- T** Training – appropriate training (including user-led training) should be available for both users and staff and could include capacity building, awareness training and committee skills.
- O** Outcomes – achievable outcomes should be set and met, if at all possible, or realistic explanations provided if not met.
- R** Resources – adequate resources are necessary, including financial support, time, facilities, appropriate staff etc to ensure that user involvement can work.
- C** Communication – accessible systems of communication are needed which exclude jargon and confusing acronyms, contain limited paperwork, and ensure a commitment to develop a system where all involved have unified objectives.
- H** Human Values – self-respect, mutual respect, sensitivity, empathy, civility and understanding.

THE IMPORTANCE OF INFORMATION

The provision of information if delivered well can have a very positive effect on user involvement, if delivered badly it can undermine its development.

The difficulty is that often we are immersed in our own understanding of information. We have been working with information in a specific way for years and seldom think of doing things differently to facilitate a different audience. When we do want to engage, to become involved with others, then the onus is on us to scrutinise closely how we produce and deliver information.

The basic question is: Does the information relay the message in a way that people can understand, or is the priority that such information fits the needs of those supplying it? This may seem obvious, but so often ways of presenting information do not reflect the audience it is intended for. We still see reams of paper used in a consultation process that contain abbreviations, jargon, acronyms and statements that only those supplying the information understand.

Information and how it is presented and delivered can be a very powerful positive tool. It can help build relationships leading to engagement. However, as in all areas of user involvement, the way things have been done in the past must be examined to see if they are now fit for purpose. There are many who find it difficult to enter this new phase of open and accessible communication.

We also see the excessive misuse of what is a very useful information tool – PowerPoint – which instead of informing audiences can leave them totally bemused. This is mainly because rather than an aid to presentation, PowerPoint is used as a visual tool to regurgitate numerous pages of text on a screen.

It is as if the presenter is talking to a computer or a screen, not really engaging with the audience. In a variety of settings, this tool has often become more like an academic presentation, and this is equally applicable to whether it is being used by someone from the voluntary or statutory sector.

If PowerPoint has to be used, it should incorporate very distinct graphics and images, very limited text and should be brief. The presenter

should speak directly to the audience and be aware of the importance of that audience, not a mouse, computer screen or projected image on a wall. PowerPoint is supposed to be a tool to help present information succinctly, not to become what the presentation is about.

If the use of PowerPoint becomes a barrier to engagement, as it often does, then forget about it. Most people prefer someone who really tries to engage with them, to involve them, to actually talk to them. Some may find this uncomfortable. If in doubt, leave it out!

It is best to keep information as concise as possible, explaining the role briefly of any organisations which are involved and giving details of any abbreviations. You may know what certain things are, what organisations do what, but do not presume that others do. A key feature of successful user involvement is the ability to put yourself in another's shoes, to see things from a different perspective.

Imagine some other profession – mechanic, joiner, electrician – each has their own technical language, their own jargon or shorthand. But if they are fixing something, they have to find different, more basic, words to describe their actions to enable you to understand what it is they are doing.

Following are two examples of information:

'The Modernisation Unit of DHSSPSNI, in conjunction with the Stakeholders Forum, have developed a strategic approach to participation and inclusion. Working closely with NISCC, RQIA and SCIE, we have endeavoured to respond to the findings of the academic research of professional staff at Queen's University in conjunction with the established guidelines. A series of meetings will be facilitated to engage users as part of our strategic 25-year plan called Wishful Thinking But No Chance!'

This example uses phrases, acronyms (without explanations) and jargon (peculiar to the relevant organisations). The writer presumes the reader already knows a lot about the topic. Following is a more accessible form of this information which is much shorter than the original but which still gives an idea what the message is about. This is only an alternative way of how to make information plainer.

'We at the Department of Health want to involve users more. With other organisations we are planning for the future. Users and their experience are very important, as research has shown. To help us to become more involved, we are running a number of meetings. You are very welcome to attend. Please telephone ...'

Ask yourself a few basic questions and test your responses with some users: Who is the information for? What do I want to say? How best can I get my message across? How can I say things differently (to replace jargon)? Can I make my message shorter? Have I explained any abbreviations and acronyms?

ROLE PLAY – ENGAGEMENT IN PERSPECTIVE

There are no easy answers of how to engage, although it is a critical requirement in developing partnership working. Following is an illustration, based on role play, which raises some key issues in relation to engagement both positive and negative. Several of the key themes highlighted through user involvement are featured in this dialogue. This role play has been used on numerous occasions as a teaching tool and has received very positive feedback.

It is recommended that for the best impact this role play should be acted out rather than just read. This is not meant to be an intellectual exercise, rather an experienced one. To add more interest, wherever possible, the roles should be reversed when acted out – a user should take on the role of Mrs Overthetop (the Chief Executive) and someone from a statutory agency should act out the role of Mr Margin (the user).

The role play is broken down into two parts/scenes, one illustrating a negative approach to engagement, the other a more positive one. There is an analysis of each of the two scenes and it is suggested that the negative issues are addressed before going on to the second scene.

This scenario, which is deliberately exaggerated, is not intended to fully reflect reality although occasionally a participant would come up after a session and say they have met a Mrs Overthetop character. This has been a surprising endorsement although originally this could not have been envisaged.

The scene is set in a headquarters office of a health and social care organisation, just on the outskirts of a major town.

The Chief Executive, Mrs Ruth Overthetop, in this first situation sees herself as a very busy person and views this meeting as an intrusion. She seems culturally locked in the past and does not look positively on user involvement. On the other hand, the Chief Executive in the second scene seems more open and appreciative of user issues. The other character, Mr John Margin, represents users as an individual user himself. It is important to appreciate the feelings of both people attending this meeting.

Scene 1 – The Negative

Mrs Overthetop – You are very welcome, Mr Margin, thank you for coming, I hope you found your way here okay.

Mr Margin – Thanks, I finally did. The bus was very expensive. By the way, just call me John.

Mrs Overthetop – Apologies, Mr Margin, I am sure you know about current budgets and cuts, or maybe you don't. And to be honest, the price of bus fares is just not a priority. Of course all this sounds good when we talk about user involvement procedures. But whoever thought up those procedures must have been from another planet and not living in the real world.

Mr Margin – User involvement, what does that mean?

Mrs Overthetop – Oh, you do not have to worry about that, we have experts here at the department who are well qualified, many with post-graduate certificates, who have worked for years with users, and they know all there is to know about you lot. Sure my secretary sent you a leaflet.

Mr Margin – I could not understand the leaflet, it was full of technical terms and things I knew nothing about. And it did not give me any directions as to how to get here.

Mrs Overthetop – Mr Margin, that is our everyday language you are talking about. Maybe if you got some training you might be able to fit in more and understand what all this is about. Or really just the bits you need to understand. Maybe we could set up a training course for you, run by my department, my colleagues might help you.

Mr Margin – But what about *your* training?

Mrs Overthetop (angrily) – How dare you! I have a PhD in Communication Studies, a Masters in Social Care Studies and a Degree in Business Management. And you dare to suggest training!

Mr Margin – I meant maybe users delivering the training.

Mrs Overthetop – Training sessions based on people moaning and complaining about services they never got and not even entitled to, trying to tell us experts what we should be doing. Then do-gooders from a certain university trying to make all this respectable. Training they call it, they would be better at home.

At this point Mr Margin gets up ill at ease and Mrs Overthetop seems very embarrassed.

Mr Margin – I think I will go now.

Mrs Overthetop – Why, what is wrong?

Mr Margin – Since I have arrived, you have shown me no respect, have dismissed any ideas that I have had a chance to put to you, and have made no effort to make me feel comfortable. You imply I know nothing and you and your colleagues are the experts. You could not even reimburse my bus fares, send me out directions or even offer a cup of tea.

Mrs Overthetop – I must apologise, I did not think you people were so sensitive. But bear with me, these user involvement guidelines mean I have a few boxes here to tick and then you can be on your way. People expect so much about consultation and engagement, whereas nothing has changed, these tick boxes will be more than enough and then we can decide how things will proceed.

Mr Margin – But ...

Mrs Overthetop – Look, just let me finish this since I went to the bother of inviting you in.

Mr Margin – Nothing has changed, I have wasted my time and money. All the talk, all the hype – nothing. Bye!

Mr Margin walks out abruptly.

Mrs Overthetop – I have never met such an ignorant, disrespectful person in my life. I knew this user involvement was a total waste of time. Maybe if they trained that lot up, taught them some manners, then we could start. But what do they know about planning and delivering services? Let's get real.

Thoughts on Scene 1

Almost everything in this scene is negative. Often it can be the small things that create barriers that prevent people from engaging. The venue for any meeting is very important. Is it accessible for the person invited in, is it convenient? Sometimes barriers around location can be overcome if the person based there is inviting, warm and engenders a sense of trust with the visitor. Perhaps a greeting in the foyer, a cup of tea, all could help. The layout of the room can also help engagement or become a barrier. Unfortunately, Mrs Overthetop sees nothing wrong with the way she is behaving. It is as if she comes from a culture where users are routinely treated in such a patronising fashion and where professionals are the experts and know everything.

Mrs Overthetop did not invite Mr Margin into her office because she wanted to hear his views. She invited him in because the policy of her department made her do so. This is what is called tokenistic. In other words, there was no real commitment to user involvement, no feeling for what it was about. Also there was no openness or transparency about the proceedings except when it became obvious that this was a tick-box exercise. I am sure this was not the transparency and openness that Mr Margin would have wanted.

At times Mrs Overthetop was very critical of the policy relating to user involvement. She was just ticking the boxes, showing that she did what she was supposed to do, but without any commitment whatsoever and with no effort to engage Mr Margin.

At the heart of this scene is how Mrs Overthetop treated Mr Margin. She was totally disrespectful of Mr Margin, ignored his wishes (would not even call him by his first name) and made no effort to make him welcome. Attitudes are a very important aspect of involvement which can help in engagement or conversely can put people off and lead to disengagement.

The basic practicalities were overlooked. No refreshments, no costs refunded, no information or directions on how to get to the meeting, no help that could at least indicate some value, some worth.

The expertise, the information, the power all seemed to be in the hands of the department (or so Mrs Overthetop thought). Mr Margin had made the effort to attend, at his own expense. He had given up his time hoping that he could engage positively with Mrs Overthetop. Nothing that Mrs Overthetop did indicated that she had any interest in engaging, in listening, in taking Mr Margin's views on board. Nothing would change as a result of this meeting. There was no engagement, no participation.

Scene 2 – The Positive

The second scene is situated in the same building. Again we have a user, Mr Margin, and the Chief Executive, Mrs Overthetop. In this scene, however, there is a more inclusive approach to the engagement. In this case the Chief Executive is more in tune with the user.

Mrs Overthetop – Good morning, Mr Margin.

Mr Margin – Good morning, just call me John.

Mrs Overthetop – Well, John, did you get here okay? By the way, just call me Ruth; we keep things very informal here.

Mr Margin – Thanks, the directions that you sent were very clear and the return taxi fare was very helpful. I have to say that having someone meet me at reception and then on top of that a cup of tea when I arrived at your reception, do make a difference.

Mrs Overthetop – I think it is the least we can do in return for you coming in today. Do you have an idea what this meeting is about?

Mr Margin – I am not saying I fully understand it all, but the information I received from your secretary was very clear, in plain language, and all those abbreviations were explained, which was a great help. I feel this has given me a good start for today.

Mrs Overthetop – That’s fine. Tell me a little about yourself, if you do not mind.

Mr Margin – Well, I have been what you call a service user for over twenty years and I think I have built up a certain knowledge of services, at least in how those services affect me.

Mrs Overthetop – I am sure you have, that is why I want to listen to you today. I know some people here still think they know everything. I would not like to think I am one of those. I have a disabled son myself and though I have not as many years’ experience as yourself, at least I have some idea.

Mr Margin – That is good to know. I feel people in your position who have direct experience often have a different, more down-to-earth attitude. Not all the time, of course, but generally I think it makes a difference. That summary you sent was useful, but I know there is more to it than just that. But to me it simply seems to be about health and social care staff getting more involved with users and carers on an equal basis and having mutual respect for each other.

Mrs Overthetop – It seems you have a good grasp of all this. I try to ensure that my staff have the same understanding. I am aware we all need regular training to keep up with things, including myself.

Mr Margin – I am so glad to hear that training is for all. For years it just seemed that users should be trained so we could fit in.

Mrs Overthetop – Look, I have a form here and I could simply tick all the boxes and for some that would be fine. I feel I have taken up enough of your time today and I know you have been invited to meet a few of my colleagues over lunch today. Would you mind coming back and chat with me again and I will send you some questions to think about? But also if you are agreeable I would like the opportunity to hear about your own ideas and thoughts.

Mr Margin – No problem, I would like that.

Mrs Overthetop – Thank you.

Mr Margin – I am sure some of your colleagues feel you go over the top with all this.

Mrs Overthetop – I do not think I go far enough, but we will discuss this further another time. Thank you for today.

Thoughts on Scene 2

Perhaps this is over the top, in a different way. Of course situations are seldom this perfect. However, Scene 2 shows how the same situation can be shown in a positive way by including several changes. In reality, often the situation will comprise different elements from each of the scenes.

From the beginning it is clear that certain barriers have been addressed in advance to try and ensure that Mr Margin feels at ease and also to reduce any stress associated with the visit. This shows a real appreciation of the user situation, an empathy and understanding of user issues and a willingness to address some of the most basic issues.

Simple things: being met at reception, a cup of tea, a map in advance, refund of travel fares, addressing Mr Margin by his first name – as he wanted – and information that actually explains something in plain, jargon-free language. These are not major costly items but

simple things that show that users are valued and appreciated. This sets a positive scene for engagement.

Whether it is always the case or not, often users find professionals who have been through what they have been through are more sensitive, empathetic and understanding. There is a rapport. This scene shows how such a rapport can be built up, how very practical things can help in this. Both scenes should give much food for thought.

IN CONVERSATION – A COMMUNICATION TOOL FOR ENGAGEMENT

It has often been said that user involvement means doing things differently. This does not mean just for the sake of it. Rather the implication is that the very nature of such involvement requires moving away from the usual way of doing something to have a greater impact.

So what is meant by ‘In Conversation – a Communication Tool for Engagement’? It is about using conversation as a method, as a mechanism, to build up rapport and engage with others. It is trying to transfer the in-depth interview techniques used by some media presenters when they are interviewing guests. By approaching the interview in a relaxed manner, although still challenging, the aim is still to develop a dialogue that is meaningful and informative.

Traditionally in the academic field, the usual means of conveying information to students is through a lecture. For the most part this seems to work. But sometimes we should consider trying something different which might work more effectively.

As someone from a user background I worked closely for over ten years with Joe Duffy, a Senior Lecturer in Social Work. It is not surprising, therefore, that at times we challenged each other’s thinking and perceptions. Coming from different backgrounds, this could be expected. However, even when on occasion we saw things fundamentally differently, our trusting relationship and our deep-rooted respect for each other ensured that we came to a compromise, or at times agreed to differ, without falling out.

As part of my involvement work in Queen’s University I was invited to give a lecture as part of the Law Module in Social Work on my experience of working with others to change government policy. This was the ‘Homes Fit For Children’ campaign detailed earlier that I had been integrally involved with some years ago which demonstrated partnership working and the potential that user involvement can have in positively changing things.

The positive outcome had a significant impact on families of disabled children as users worked with professional social care and housing officials in tandem with politicians in creating this significant change.

For a number of years I delivered the lecture on this subject to social work students and at times there could be up to 120 people in the audience. Recently I have reflected on this aspect of my life's experience. I was not a lecturer, lecturing was not part of my usual activity, and I felt very uncomfortable in carrying this out. It is probably fine for someone who regularly lectures as part of their work but it wasn't for me.

The main difficulty I had was standing in front of such large numbers and trying to engage. It was as if at times you were talking *at* people, not actually talking *to* them. And because the students were in full view, I could see at times that a few seemed preoccupied with other things, which is understandable and not meant to be a criticism. At the very heart of this discomfort was the knowledge that I was trying to get across a very personal message that was at times emotional to an anonymous audience that must have found it difficult to take in, within the context of a lecture in a large auditorium.

I just did not think it was working the way I wanted it to. Fortunately, my relationship with Joe Duffy helped to explore this issue in depth. I pointed out my concerns to him and offered a possible trial solution in time for the annual lecture of 2017. We explored this idea which I labelled 'In Conversation'.

We decided to give this innovative and challenging approach a go so preparations began. Even though we knew each other well, we still needed to prepare and plan the 'In Conversation' session. So Joe and I prepared our own dialogues separately then we shared these with each other and applied any agreed amendments. We made sure we knew this dialogue in advance.

Ironically on the day we left aside the dialogue and carried on without it as our confidence grew. But it is important, I believe, to have some prepared dialogue as a back-up, just as it is equally important that 'In Conversation' is carried out by two participants who know each other well and have a track record of working with each other.

Practicalities are also very important. Two comfortable chairs or sofas are preferable, with the two participants facing each other at an angle but whose faces are still visible to the wider audience. The set-up should be more informal than a traditional lecture hall setting,

maybe with a small table but not too many distractions. Also clip-on mikes are essential rather than stand, table or hand-held mikes as these can be very distracting.

If possible, dialogue should be natural with back-up written materials on hand at first which hopefully should not be needed as the session continues and the participants generate a relaxed facilitation process.

At the end the students are invited to ask questions. For me, the daunting lecture scenario has been transformed into a comfortable chat with someone I know well which has created a more enjoyable experience.

Does it work? It is probably too soon to say definitively. Over time there will be opportunities to comprehensively assess the merits and/or the disadvantages of this approach to engagement. Feedback is essential to this and any other tools for engagement. However, early anecdotal comments have generally been positive. At a personal level I found this approach was much less stressful than giving a traditional lecture and far more satisfying.

Although not an empirical measure, it is worth noting that several days later when involved with a Skills/Preparation for Practice exercise with 14 students, all of them chose the housing campaign featured in the 'In Conversation' talk as the basis for their interviews. They decided not to base the role play on the case study provided by the user as had been normal practice in recent years.

In subsequent months, the senior lecturer and I again used this technique in a user-focused conference and in a workshop on simulation and role play in relation to medical studies and social work. Again anecdotally there was positive feedback. However, if this form of engagement is used in future exercises a more systematic evaluation will need to be carried out. It is much too early to draw conclusions.

User involvement in social work education has come a long way from those early days of guest user speakers. Staff champions of this concept in the universities have helped to break down early barriers, faced the challenges, and have been facilitated by policy directives that have been more positive than previously.

Users themselves have at last recognised their own experience and knowledge and understand how they have so much to offer social work students, facilitated by many excellent sensitive university staff. Students themselves are beginning to appreciate the critical role that user involvement has in their studies and in their future practice. True partnerships are emerging based on trust and respect. But all this takes hard work and commitment as not everyone is convinced of the value of user involvement.

As user involvement becomes more embedded in social work education and training, it seems that such an influence may lead to the consideration of exploring innovative tools to facilitate engagement. Hard work and commitment alone will not change attitudes and perceptions or convince the sceptical.

Users are now regularly involved in social work education in a systematic way and not an occasional guest as in the past. Users are valued and respected for their experience and knowledge and even paid for their work and reimbursed for expenses, which would not have been envisaged in the past.

Users are commissioned as researchers on a par with other researchers and paid accordingly. At times they are replacing drama students and social work student colleagues in skills exercises as part of Preparation for Practice interviews and even contributing towards the student assessment.

In the context of such innovative changes, perhaps 'In Conversation' could become the next tool for engagement. Just imagine standing in front of 120 students, would you not rather sit down and have a chat? 'In Conversation' is simply about that.

DIFFERENT APPROACHES TO USER INVOLVEMENT

User involvement is enriched by the variety of forms it takes. Such different views give us an opportunity to compare and contrast, to see what works in one situation and what may not work in others.

It may be a surprise to some but there are users who are genuinely not interested in this subject. It is just not on their agenda; they just want to get on with their lives. It is not that they passionately disagree with issues around user involvement, it simply has no relevance for them. This could be viewed as apathy or we could simply acknowledge that, as in other areas of life, not everything that interests one segment of society captivates others in a similar way.

There are users who have been hurt by broken promises, whose expectations have been falsely raised, dashed by lack of feedback, meaningless outcomes (if any) or even rudeness or lack of respect.

There are people, however, still eager to engage; they desire real change and are willing to work positively with those who can help create change with them. They often see the bigger picture and are determined to address any negative issues or barriers.

They are confident of their own ability and acknowledge the ability of others. Partnership working has real meaning for them. Work and life have taught them the true meaning of user involvement and the potential for change it brings. They have not been bought out, as some people assume, they have bought in.

To appreciate in any critical way the concept of user involvement it is vital that there is a genuine understanding of its context. Those who plan and deliver services do not always fully buy in to this idea.

There are some who provide services who simply tolerate such involvement because policy dictates they have to but carry out the very minimum they can get away with, pretending that they have engaged. As long as they are seen to be doing something, it does not matter how little or indeed how effective, it is simply outward appearances that matter and how to make sure this can be demonstrated.

Some simply tick the boxes – they just make sure what has been set out to do is done, no more, no less and really how it is done does not matter to them. It is not just outward appearances that matter,

but the actual letter of the law, not the spirit, the letter. The reality is that some people, thankfully a minority, in statutory agencies do not want to work with users and only do so because it is a statutory requirement, they have no feel for what they are doing.

Yet others will claim they have no money, time or support to develop user involvement, but surprisingly it seems they may have resources for everything else. In other words, it is not a priority.

Finally, there are those who provide services who believe, and have so often demonstrated, that user involvement can and does work. No-one is saying it has been easy for them, but they are willing to work at it as they see the value and benefits of persevering. They are often the leads in many statutory and voluntary agencies that have been instrumental in initiating or nurturing models of good practice in user involvement, models that have in practice not only worked efficiently but have informed and encouraged others.

In recognition of the growing importance of user involvement, as identified and expressed by users and user groups, the NI statutory sector introduced several initiatives over the years to assist in embedding the concept into their ongoing work. These include:

Personal and Public Involvement (PPI)

On 26 April 2007, the Department of Health, Social Services and Public Safety in Northern Ireland, now known as the Department of Health (DoH), endorsed 'Guidance on Strengthening Personal and Public Involvement in Health and Social Care'. Later that same year (September 2007) this guidance was circulated widely to the relevant statutory health and social care organisations.

Sometimes there is confusion over what is meant by the term 'Personal and Public Involvement'. In essence it is quite simple. When it is stripped back it is about the involvement of different people in health and social care in Northern Ireland. To go further, when users, carers, patients, staff and management engage with each other in how health and social care services are designed, planned and delivered, we then have the basis of Personal and Public Involvement (PPI).

The Public Health Agency captured this in their early definition:

'PPI is about involving those who use services, or care for those who use services, with those who plan and deliver services. This involvement can sometimes relate to individuals or part of a group (personal) or voluntary groups or the wider community (public).'

However, in my opinion Personal and Public Involvement is not user involvement, even though it does involve users. It is a response to involvement from statutory health and social care organisations and agencies, a top-down approach. User involvement primarily comes from users themselves, a bottom-up approach, and this predates Personal and Public Involvement.

Later (2009) legislation, called the Reform Act, enshrined public involvement as a requirement for specific statutory health and social care organisations.

Implications for relevant health and social care organisations:

- To have and to demonstrate effective public involvement as it is central to their delivery of safe, high-quality services.
- Involvement relates to planning, commissioning, delivering and evaluating services.
- Ensure that involvement 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 proactive engagement with others.

Is PPI Effective?

In 2015, the Public Health Agency and the Patient Client Council commissioned a research project into PPI in Northern Ireland. The findings and recommendations from this research were publicised and circulated in the summer of 2016 and were primarily about the effectiveness of PPI.

A consortium comprising Queen's, Ulster University and PPI personnel from the Health Trusts, working with users and carers, secured this commission, led by Joe Duffy who has written extensively on user and involvement issues and leads up user involvement in social work education at Queen's.

The title of the research was: 'Personal and Public Involvement and its impact – Monitoring, measuring and evaluating the impact of Personal and Public Involvement in Health and Social Care in Northern Ireland.'

The remit of the work was to identify good practice, barriers and ways of overcoming them, and how to measure and evaluate PPI activity with users and carers at the heart of the research throughout. The research had three methods of gathering information: literature review, an online survey and focus groups. At the time this was one of the most comprehensive studies of PPI in Northern Ireland.

Report Recommendations

The following recommendations were made for the appropriate statutory bodies to consider and act on:

1. Allocate adequate and dedicated resources.
2. Raise awareness of the meaning of PPI.

3. Define more clearly what PPI is.
4. Employ dedicated PPI champions in Trusts.
5. Use social media and internet technology to publicise good news stories and to promote a one-stop shop for information provision.
6. PPI activities should be evaluated to measure their effectiveness.
7. Generate feedback on all PPI activities and this should be used to influence practice.
8. Provide adequate dedicated training courses to support PPI.
9. Questions on PPI should be part of interview process, performance appraisal, job description and inductions. Users and carers should also be part of staff selection.
10. Accountability should be part of PPI, particularly at senior management and director levels. There should be a continuing review of PPI by the Health and Social Care Commission.

This research, the policy and guidelines on PPI, important as they are, certainly are not the full story. Over the years to a greater or lesser degree, this involvement process has become embedded in the work of the Health Trusts, the Public Health Agency and the Health and Social Care Board.

In the research there is a section on examples of good practice relating to the impact of PPI. The report also looked at what actual difference PPI has made. Some of these differences are quite significant: service improvement, an efficient use of resources, improved user outcomes, greater transparency, improved staff morale, services tailored to need, fewer complaints and service users influencing planning for their own agenda. This list is not exhaustive.

Just because in statutory health and social care organisations PPI has become a statutory obligation does not necessarily make engagement and involvement easier. The history of user involvement predates PPI and the issues associated are not new. Legislating in relation to engagement may be a positive move but it does not offer a solution to those who are just not willing to get involved.

Often those leading on PPI have a range of other duties and just do not have the time, energy or resources to effectively develop PPI. Some people leading on PPI feel they are out on a limb with no support, and although in theory most employees have a responsibility for PPI often it is left to the lead to do most, if not all, of the work.

The 10,000 Voices Initiative

The 10,000 Voices initiative is led up by the Public Health Agency and the Health and Social Care Board working with the six NI Health and Social Care Trusts. It aims to collate feedback from as many users, patients and staff as possible on specific services and where possible to act on this feedback.

The experience of patients, users and clients is recognised as an integral part of high-quality care.

This initiative is not simply about providing a mechanism for them to share their experience of health and social care services. Significantly it is also about affecting and influencing the way services are commissioned and delivered.

This project began in October 2012 and has certainly shaped some services as a result of an extensive engagement process. It is about listening to patients, learning from them, improving their quality of services and enabling them to influence how services are designed for the future. The views of staff also became an integral part of this work.

In response to the findings from one survey under the 10,000 Voices initiative, certain actions were taken. To enhance communication Trusts introduced staff name badges and encouraged staff to introduce themselves – this became known as the ‘Hello, my name is ...’ campaign. Patient information leaflets were updated and improvements to communication of mental health issues have been enhanced. Basic comfort needs in general were reviewed and the cleanliness of waiting areas was revamped as well as the provision of snacks and drinks. Staffing levels were looked at as patients had concerns over the pressures that staff were working under.

Learning from this particular method, it was found that 10,000 Voices is a mechanism to capture, understand and improve the patient experience. But it was also a forum that allowed an innovative and ideal way to engage in partnership working with users and patients. Most of the recommendations from the various reports emerging from the initiative relate to implementing key policies and guidance to improve patient care.

What initially could be perceived to be another tool available for people 'to tell their story' has, I believe, matured into a very methodical, yet accessible, driver for change which is inclusive, patient/user focused and incorporates the knowledge and experience of staff who work directly with the public.

The initiative proved to be so successful that a follow up, 10,000 More Voices, was introduced in January 2019.

Co-design and Co-production

At the end of 2016, concepts such as 'Co-design' and 'Co-production' came to the fore in the field of involvement in Northern Ireland. Co-design and Co-production are when citizens are involved in the creation of public policies and services. They do not replace 10,000 Voices or Personal and Public Involvement. Rather, they are additional tools (which are not new as some people believe) that can be scrutinised and used where appropriate.

Co-design is designing services together. Co-production is about working together to produce services, with users, patients, staff and management collaborating on an equal basis. Both are about involvement from the outset, valuing the expertise of users and carers as well as staff and management and a sharing of responsibility in planning, designing and delivering services.

At a local level, where Local Commissioning Groups help identify and plan services, Co-design and Co-production are integral to their work. Similarly, there are groups called Integrated Care Partnerships working within health and social care who plan specific projects and again their membership includes service staff, the community and voluntary sector alongside users and carers incorporating this way of working.

We are all aware of the pressures on health and social care services in Northern Ireland. Lack of appropriate funding, fewer opportunities to develop new services, professionals raising real concerns about the future of specific services, increasing waiting times for some services etc are all critical issues at this time. Changes in structures and the transformation of services are very unsettling, especially for the staff involved who are not sure where their future employment will be.

When different concepts are introduced (such as Co-design and Co-production) there can be a perception that these replace what went before. In this case, because PPI is no longer at the forefront, it has disappeared in some people's minds. Nothing can be further from the truth. PPI is the statutory policy in relation to involvement; Co-design and Co-production are just two of the tools that can be used in trying to develop involvement.

A practical example of the introduction of Co-design and Co-production is evident in some consultation processes. Previously, consultations were designed and produced primarily by staff in statutory agencies. In certain circumstances now, some consultation processes begin with what is called 'pre-consultation' where users/patients are involved with staff to help design and test consultations before they are produced and delivered and the full consultation takes place.

In reality, these terms describe what was happening in previous years in the community. Trust staff were working with users and patients on specific projects in real partnership, long before involvement became a statutory duty. It is not about the latest concept or idea, rather it is how we all can work together.

Other Views

In the Family Information Group's book *The Way I See It* there are different views on user involvement. These views have become the positive voices in this field of work, encouraging many others who for one reason or another are struggling to engage. Some of the messages are not new but they have added value as they come from those trying to define and facilitate engagement and partnership working.

Whether it was within the corridors of the Northern Ireland Children's Hospice, or the lecture rooms of Queen's University, or a local Day Centre – the messages were the same, user involvement does work.

So many other contributors agreed – whether parents and users themselves, or staff working in statutory or voluntary fields, emphasising that because it works, they wanted to work it. The book highlighted several models of good practice, models that helped others try the same in their own setting.

User involvement is not theory; it is lived by users. User involvement is not impossible; it has been made possible. User involvement is not a pipe dream; it is very much reality.

That reality in *The Way I See It* was reflected upon by parents of disabled children, by key people in voluntary and statutory agencies and by academics. They found in their own work and the work of others that this involvement makes a real difference. The book contains many examples from Northern Ireland and England of how user involvement works in practice. A number of these examples are the result of many years of effort, they just do not happen overnight.

These examples show that user involvement is alive and highlight the need for it to be sustained and meaningful. Although time has passed since the publication of *The Way I See It* and some people have moved on or sadly passed away, the sentiments expressed are still valid and relevant today.

Following is a selection of quotes from the book which illustrate the different viewpoints that could help inform the debate and discussion on user issues.

'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.' (Anne, user)

'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.' (Martin McCafferty, former Day Centre manager)

‘User involvement takes time, effort and commitment, but it is very rewarding and can help towards positive change.’ (Maria Fox, formerly of Gingerbread Northern Ireland)

‘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.’ (Anne-Marie Gallagher, formerly Creggan Country Park)

‘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.’ (Tina, user)

‘Sharing expertise and having an agreed focus is the only way forward. It is cost-effective and it also makes common sense.’ (Paul Hipsley, Guildhall Press)

‘This is what user involvement is about. Simple ideas, common sense, but very often ignored in the past. It takes hard work, commitment, perseverance and honesty – qualities we carers have been used to for years.’ (Christy, carer)

‘People have a right to information – the right information, at the right time, in the right format. Communication must be more than simply information provision.’ (Keavy Sharkey)

‘By listening to the views of users/carers, professionals can gain a depth of knowledge that a textbook may never offer.’ (Mary, carer)

‘I am not sure of all this user involvement stuff. It does seem at times 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.’ (Siobhan, user)

If something works, surely we can learn from it. The knowledge gained from those who gave these quotes and from the examples of good practice in *The Way I See It* must help us to understand some of the elements critical to user involvement.

Have we really listened and have we acted on what we have heard? These quotes are about going beyond the reading and listening, it is about understanding and acting. It is surprising that most of these distinct and different voices could gel together to give such powerful, clear messages. Even though most of the contributors have never met each other and probably never will.

USER INVOLVEMENT IN ACTION – THE HIVE ASSISTED LIVING PROJECT

Much has been written about user involvement. There have been theories, policies, action plans, standards and numerous academic articles on the subject. In one way or another these have contributed to the development and understanding of what it means to engage, to be involved.

In the past I have seen the negative and positive influences on such involvement. I have witnessed when involvement is done badly and haphazardly and the horrendous impact it can have on people. Equally, I have seen lives changed positively when the right approach to involvement is taken. As I no longer work directly in the community, I seldom nowadays see the impact of involvement except perhaps through strategic projects and initiatives. Until recently that is.

The reality of involvement, for me, must be more than words; it must be action, action that directly affects people's lives. In 2018 I was made aware of a project developed by Creggan Enterprises in Derry and delivered by their in-house technology entity called The Hive. I had been aware of The Hive's work in the community championing the use of technology and the media with individuals and groups and particularly training young people. But this new project was quite different and very innovative.

The Hive project concentrates on housing and associated facilities and services for disabled people and their families. They have researched this subject and consulted with professionals in the field of health, social care and housing. Equally importantly, they have engaged directly with disabled people and their families (users).

User involvement is about partnership working and sharing expertise. In the pre-planning and development of this particular project The Hive merged their extensive skillset with those with an expertise in housing provision, the NI Housing Executive (NIHE), and incorporated the knowledge and skills of occupational therapists from the Western Health and Social Care Trust (WHSCT).

User involvement in housing and adaptations is not new. Paraig O'Brien (senior occupational therapist and NIHE Liaison Officer) and

colleagues produced a comprehensive research publication on the subject over ten years ago. But The Hive project is a very specific trial and not a general housing design feature.

So what is the project? The concept is to use assistive technology to enhance the quality and safety of individuals with a range of disabilities in their own home. This is done through smart technology in an inclusive way. The full title is the 'Assistive Technology Pilot Programme'. It is supported by NIHE and WHSCT, particularly in co-operation with local occupational therapists, and is administered by Hive staff. It is a pilot programme which will run for a year. If it is successful, consideration will be given to expanding this concept further and wider into the community. In February 2019 the project won the Chartered Institute of Housing (NI) 'Working in Partnership' award with NIHE.

The process is straightforward and collaborative. The NIHE identifies tenants it believes could benefit from the pilot. The occupational therapists carry out a user focus assessment of need for those identified. The Hive engages with the tenants to gauge their level of knowledge of technology and to help tailor individual specific needs to the technology. Ciaran is the technology assistant with the project. He is also the key contact for the families involved and takes the time to get to know each of the individuals and their families. He is the human face of The Hive and plays a critical role in the development of user involvement through nourishing trust. He also facilitates any training requirements.

Up until relatively recently aids and equipment around disability could be very intrusive and indeed expensive. Modern technology and voice-assisted equipment such as the Amazon Alexa smart speaker are very neat, cost-effective and compact ways of addressing independence and safety. Disability can lead to dependence, insecurity and at times isolation.

With assisted technology provided at no cost to the user through this project, carers can reassuringly leave loved ones comfortably at home, while monitoring them remotely via a range of digital devices. They can check on their relative's health and wellbeing similarly. A tenant user can check who is at the door before opening it remotely

using the Alexa system, a very reassuring safety procedure at a time when break ins are very prevalent in our society.

Users with mobility problems can comfortably turn on lights, their heating, the television, radio and even remotely in another room the kettle at the touch of an app or a message to Alexa – real quality of life. For safety, key contacts have been built into the system so users can immediately get in contact with a key relative or friend or perhaps phone the doctor, social worker etc without having to find the number. Alexa can also be programmed for reminders such as appointments, prescriptions etc. Another safety feature, particularly if someone is out, is the facility to turn on lights remotely so that to outsiders there seems to be somebody at home, another useful safety feature.

I was invited by Hive staff in the early stages of the project to visit the homes of several of those using the system. There was a range of people of different ages with a variety of conditions, some directly impacted by disability, while others were family carers. As someone who is not an expert with technology, I was taken aback at how adept the people I visited were, particularly some of the more elderly ones.

A lot of this confidence in using technology is down to the assistance given by Ciaran, particularly in the early days. He was mentioned frequently by the users of the equipment in a very positive way. The families felt he was always there when needed which was very important to them and his influence and contribution cannot be underestimated.

What also impressed me was how much the technology had become part of the users' lives; it was integrated and inclusive. It seemed that as others used technology in their everyday lives so did they, they were not different. Indeed, they were equally as confident and capable, not excluded but involved. I saw at first hand the difference such small things could make in people's lives as they became more independent, relaxed and most of all in control.

I heard about the benefits accrued, their experiences and indeed their gratitude to all involved. Many said that their lives had been transformed. It was more than words, it was a feeling, an empathy, that technology, delivered in this way, has helped them move on.

When this pilot project is concluded, a detailed user-focused evaluation will be carried out. I am confident the ethos that brought this project into being will be sustained and it will be expanded. Equally as important will be discovering what engaging with the project and those who administered it has meant to the users through their own voices and finding out what impact, difference and benefits have resulted.

These findings will be much more than words; they will be the real-life experiences of involvement from those directly involved. Is this not what user involvement is really about?

CONCLUSION

This began as a very personal experience. At that time, I could never have envisaged where all this would go and I would never have imagined how such an individual set of circumstances could impact not just me and my family but the wider community.

I came from a position where user involvement had absolutely no meaning and I had no understanding of the issues relating to it. Through time, however, as our son Donovan's advocates when he was very young, we experienced user involvement issues first hand, even though initially we were unaware of the term. Our reality, our personal knowledge and experience, became our early teachers. Lessons learnt then would remain with us for a very long time. User involvement was more than words. The importance and relevance of that personal experience is emphasised throughout this book and underpins my own understanding of involvement issues.

In our relationships with the professionals involved with Donovan, we came to a better understanding of working in partnership, being engaged albeit at a very personal level. The principles underlying involvement at this very practical level were beginning to sink in as we appreciated how building very effective and meaningful relationships could make a real difference to our lives and those we were working with.

As a founder member of the Family Information Group, little did I know what this small entity could achieve in such a short period of time. Yet it has to be understood that my own understanding of user involvement, although informed by personal experience, was nurtured and deepened by those I collaborated with in the voluntary and statutory sectors as part of my work. Important as these influences were, the real impact of user involvement – more than words – resulted in my contact, relationships and work with parents and families of disabled children, particularly our group members.

As our group went on to campaign on the issues that impacted families most from their perspective, we continually broke new ground and became fearless in our challenge to authorities. In this book full justice cannot be given to the housing campaign, but

I hope that readers can get a flavour of what was a momentous achievement. This example, more than anything else, taught many of us the potential of user involvement for positive change. Through understanding user involvement our group members began to realise that we were not the only marginalised people in the community and that we had so many issues in common with others. Hopefully this is reflected in this book.

No-one is saying that user involvement is easy. There are many barriers and they are highlighted in this publication because barriers will not be overcome if they are not first identified.

Involvement is also featured in the details around Personal Public Involvement, 10,000 Voices, 10,000 More Voices, Co-design and Co-production. Although not user involvement as such, I would continue to contend, these areas of work have the potential to create real change. It is hoped that this book will help to enhance the understanding of user involvement and associated issues. It is intended to create debate and discussion and it has to be remembered that the thoughts and ideas discussed here are only a perspective, one person's viewpoint. They are very much open to challenge.

It is important in the current climate that we explore these issues. We know that presently there is underfunding of services such as health, social care, housing, education and a range of other public services. We are all fully aware of the excessive waiting times for specific health and social services. Over the past number of years efforts have been made by those in health and social care to transform the design, planning and delivery of services.

This does not all happen in a vacuum, as report after report advocate more involvement for users/patients. User involvement will not solve all the problems as additional financial resources are needed. But if we fully understand the nature of involvement then the shared experience and knowledge of users, staff and management could be channelled more effectively into the design, planning and delivery of services.

If services are designed and planned with such input from the outset then it is perfectly conceivable that they would have more to offer, be more cost-effective and actually would have the potential to help prevent some illnesses and diseases. The users who have first-

hand experience of receiving services would be involved in these processes. There is an opinion that real change can only happen when it comes from the bottom up not the top down as has happened in the past. Only when people buy into something can it work.

Maybe one way of achieving this is to radically look at the way things are done.

The Nuffield Trust is an independent charity which aims to improve health and social care through research and has produced a series of reports looking at health systems in the UK. In July 2019, based on work carried out in 2018, the Trust produced a report on change (or the lack of it) in Northern Ireland's health system. Some key issues that emerged in relation to involvement are:

- Co-production was seen as a pretence by some of those interviewed and did not create the partnerships it was intended to do.
- Top-down working was increasing.
- Trying to achieve immediate changes, rather than long-term aims, will slow progress in the future and actually make things worse rather than better.
- Engagement with communities by the NI health and social care system has been poor or inconsistent over a period of time.

In this book I have already raised misgivings about certain concepts including Co-production. The findings from this report give real cause for concern and it appears that others also have serious reservations.

Furthermore, issues in relation to engagement (or rather the lack of engagement) with communities undermine the confidence to some degree of those wishing to pursue the involvement agenda in an inclusive way.

Also very concerning is that currently there is a top-down approach to service planning and delivery. As changes in the structures of the health system continue, this can only increase. The fundamental argument in this book is that user involvement is a bottom-up approach and such involvement cannot be effective if it is approached in a top-down manner.

Finally, change has been slow and many of the promises and aspirations around what is called 'transformation' seem to have either floundered or been delayed. Yet change is needed, and change at a reasonable rate, if effective inclusive involvement is to happen.

The comprehensive analysis of the current state of the Northern Ireland health and social care system in the Nuffield research report has raised many other issues that need to be addressed. The report, nonetheless, is timely and as an independent view must be taken seriously if together we are seeking to improve our health and social care system in Northern Ireland.

Everything seems to be so separate when it comes to involvement. There should be no competition, elitism or snobbery, rather a unified co-ordination of the tools that are being used in regard to involvement. Different approaches are fine, but there should be one concept.

There are still difficult decisions and choices to make. But there is a way forward and hopefully this book will contribute to this, with users central to all future planning.

THE WAY FORWARD?

Involving people in the design, production and delivery of services is challenging, no matter who they are. In this book I have looked at many examples of this. From my experience of involvement, I have drawn my own conclusions and certainly these are open to challenge or criticism. I have taken this opportunity and platform to summarise here the issues that are important to me which I believe need to be addressed if we are to find a way forward towards more effective involvement:

- The user experience and knowledge must be accepted as being equally valid and valued as academic and research evidence.
- Language associated with involvement must be standardised, accessible and understandable with the elimination of terms such as PPI, Co-design, Co-production and stakeholders.
- A new concept should be introduced to describe engagement, simply 'Involvement in Health and Social Care'.
- The consultation process has to be reviewed and updated to ensure that users are involved from the outset, that there are no preferred options, and that outcomes reflect the findings from the consultation.
- There has to be a clear understanding and appreciation of the difference between users being invited into statutory engagement processes (top down) and user led involvement (bottom up).
- All statutory engagement services should be brought together in one department, co-ordinated with a partnership ethos where learning is shared and disseminated. There should be no hierarchy of involvement delivery.
- The monitoring and evaluation of engagement processes should be systematically carried out and regularly reported on in public.

- A dedicated user advocate post or entity should be created to ensure and enforce proper implementation of all agreed user engagement or involvement processes.
- The focus of involvement should be the development of safe, high-quality services.
- Staff, management and users must be equally valued and appreciated.
- Where appropriate, we must do things differently in service design, production and delivery to ensure and guarantee a continued and constant better service for users.
- There must be a culture of openness, honesty and accountability whereby healthcare staff have a duty to patients/users to inform them if something has gone wrong, to apologise to them for any distress caused, if possible to put matters right, and to explain fully the impact of what has happened.
- All relevant information must be presented in formats and media that are accessible to the diversity and capacity of users.
- Adequate resources must be invested in this work, involvement should not be viewed as merely an optional add-on.

USER INVOLVEMENT IN LITERATURE

Very few of us involved in the Family Information Group would initially have been aware that others were writing and researching about the issues affecting disabled children and their families. We were so tied up in our own lives and meeting the responsibilities of trying to address the issues impacting our disabled children and ourselves. The reality is that even today very few users are actually involved in research on these issues, or write academic papers or other literature, even though their lives may be the focus of them. Primarily it is researchers, lecturers in universities and higher and further education, those working professionally in housing, health, social care and other related fields who carry out such work.

Many academics or professionals increasingly have experience and knowledge of working with users and user issues, which is reflected in the literature they have produced in recent years. Although this literature can at times seem disconnected from real life, and indeed can be very difficult to read and understand, it should be noted that most of this literary output is based on interactions with users and the user experience.

Academic research is considered by many people involved in design, planning and delivery of services as relevant evidence which informs the work they do. In the past very few users were involved in this type of work. What is encouraging, however, is that currently some academic researchers are engaging users as co-researchers and I believe that this can only contribute positively to that research. User involvement should, however, not be allowed to simply become an academic subject; it is much too important for that.

There are many different aspects to user involvement. There are the users, staff and management who work with them, educators, the various professionals involved and there are those who study, observe and research such involvement. Some of us may have a difficulty with understanding the language and concepts used, or if the truth is told may have no interest as real life takes priority. Literature has its place and many genuine advocates for user involvement are involved in this work and contribute to positive changes.

As this is not an academic publication, there are few literature references. In acknowledgement, however, of the impact of findings in this field, a concise summary of key recommendations from across the spectrum of published research is listed below.

Recommendations from Literature Review

- User involvement values and principles should underpin all projects.
- A partnership and collaborative approach should be taken in all projects.
- Barriers to engagement should be identified and addressed through action plans where appropriate.
- Do not reinvent the wheel – models of good practice in user involvement should be researched and identified and lessons learned from these.
- There should be equal weight given to the value of local, regional and international models of good practice.
- Gaps and fractures in service design and provision should be identified collaboratively with users, researchers, voluntary groups, health and social care staff.
- All information should be accessible (including any website) and meet the requirements of those who use it.
- User-led training should be mandatory for all those in user involvement legislation.

FURTHER READING

Much has been written about involvement and related issues from different perspectives. A selection of these literary contributions to the wider debate is listed for anyone who is keen to find out more about this subject.

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