

USER INVOLVEMENT

More Than Words



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INTRODUCTION

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

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

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

Sometimes the views of individual users take second place to those coming from groups. User involvement cannot work without them. At times it appears that those who could have the most critical input as to whether user involvement will be effective, are overlooked.

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

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

DEFINITIONS

It is so easy when making definitions to get caught up in words, in what is politically correct or indeed to follow current trends. Below are some explanations for key words used. Other terms will be defined as they arise. It must be stressed that these explanations are only used in relation to this publication, it is acknowledged that these definitions are very much open to debate.

Exclusion simply means lack of involvement at any level.

Inclusion is where involvement makes a real significant difference with outcomes.

Partnership is about working together, based on mutual respect.

Staff are those in paid employment, in statutory services and this category will include a variety of roles of those who engage with users. Statutory agencies have to provide services by law.

Tokenism is where involvement makes no real impact at all, and could be seen as simply fulfilling an obligation.

User means someone who uses services.
Although this will primarily be in the health and social care fields, it can also apply in other areas where people use services.

BACKGROUND

For some, people user involvement is a new phenomenon. For users, it has always been there, whether they knew about it or not. The fact that people were using services meant that they were involved with those who provide services. At times many have not been fully engaged, at other times it has been a tokenism and for some it has been a positive inclusive experience.

User involvement has been interpreted and misinterpreted over the years. There have been fears that inclusion will result in completely overthrowing systems and ways of working. At times barriers have been identified why it could never work. Some organisations believe involvement of users is user involvement.

This booklet is not an attempt at an academic exercise, rather it aims to continue and deepen the ongoing debate around user involvement issues, albeit from a user perspective.

User involvement is not static, it changes and develops. By exploring this in depth, by pointing in the direction to other writings on this issue, this

should help those who wish to positively develop and nurture this idea.

The expertise and knowledge of users is central to any discussion on user involvement, as it is from their experience - often ignored in the past, where this concept originated. However involvement also requires partnership working, it cannot stand alone. Partnerships need others and this is why staff delivering services are an essential element in all this.

User involvement is also about choice. Users must choose if they want to engage and in what way. Information, communication and support can help with this but in the end it is still about choice, informed choice. Literature, policy, legislation and procedures may all create positive conditions, but it is users who live this out and who have to make the choices. It is partnership working with staff that can make these choices impact reality in a positive way. It takes both - users and staff.

CULTURE CHANGE

To fully engage with users, there may need to be a culture change. These words are not that of a user but come from DHSSPS Guidelines on Personal and Public Involvement (PPI, 2007).

What is this culture? What has to change? This is open to interpretation. However it could be interpreted that historically those who plan and provide services know best. Staff are trained, qualified and educated, they do not need someone else, particularly a user to tell them how to do their work.

How could a user have the knowledge and expertise when they are so busy with their own personal lives and have not had training, do not even know the words and they are so focused on their individual life that they could not see the big picture. A professional elitism grew up over the years which was very difficult to penetrate.

As rights began to infiltrate needs. As users began to find their own voice. As “scandal” and enquiry highlighted failings in the “system.” As the media took a more pro-active investigating role. Professional elitism and “we know best”

began to take a knocking and legislation, guidance and policy began to reflect these changes. There are a number of factors that contribute to making up culture. Some of these are more to do with society, the community, the place, the time rather than the individuals who have become what is now called users.

But it can be stated that in one generation, there has been at least a gradual move away from the notion that there are only one set of elite experts who are experts by profession and education, rather than experience. Of course there is still resistance in some areas that users can also be experts, but at least now user issues are on the agenda.

LITERATURE AND REFERENCES – NOTHING NEW

Below are several references in relation to user involvement and related issues. Although these are important, even more significant is the dates. Almost twenty years ago, and perhaps even earlier, involving people in planning services was discussed. If there is nothing new, why has user involvement taken so long to effectively impact? Is it culture, or something else?

Current research facilitated by Joe Duffy at Queens University, DHSSPS Guidelines on PPI and other relevant research findings are helping to further the debate on user involvement and to examine how it practically works. Such work is essential in helping good practice that already exists to have a platform, it would not otherwise have. But also in some cases, the process involved in facilitating research, is in itself a model of good practice, this is particularly true of the work of Joe Duffy.

Further references in the Bibliography re-emphasise a number of issues that have now become to be associated with user involvement. Legislation such as the UN Convention on

Human Rights, the Children's Order, Equality Legislation, Disability Discrimination Act have firmly ensured that user involvement and engaging people are grounded in rights, they are not the gift of someone in power.

Alder Hey (2001), Shipman (2004), Victoria Climbié (2003), Donaldson and Foster Reports (2006) have all highlighted, at different times, gaps and failings in systems which have implications for those who deliver and use services. Concerns have been raised through these reports about statutory agencies not listening attentively to users, not taking their views seriously, lack of consultation and/or consent, insufficient training for staff or unsuitable procedures allowing users to raise issues.

These reports collectively highlight what in the past seemed to work, is now open to question. As a result of the findings in these reports, action has been taken at government level, which has helped, at least in some way, to engage users. It is now more acknowledged that users do have an expertise, that they should be listened to, that there has to be ways in which they can raise issues and staff do need training to facilitate this. Some of these themes continue in literature and

research particularly the rights basis for user involvement and the acknowledgement of the expertise of users. In other words, the right for users to have a say and a significant say, at that, is featured in quite a lot of the literature.

In much of the literature on research, there is discussion on the ethics of research, on the use of research as a basis for empowerment and questions asked about the ethics involved in research. One key issue is that although children are users, they seldom are listened to, their views are not often taken on board and often others speak for them.

Extensive research has also afforded the opportunity to look at values around user involvement, critical values such as respect, trust, dignity, collaboration and a commitment to keeping agreements. These values are the backbone of models of good practice in user involvement.

There has also been a move through the research towards a fuller engagement of users, looking at innovative methods of trying to engage and ensuring that voices are not just heard, but acted on. From identifying users as having the same power as other consumers, to where users

control research and lead up the involvement process rather than just responding.

Whether it is government legislation, policy guidelines, findings from enquiries, literature or research, the messages on user involvement are clear. Engaging users is here, it has been for some time, and there is plenty of guidance, advice and information available on how it can work, and how it can work effectively. Academic studies and research have given us a real opportunity to explore some of these issues in depth and have enabled us to reflect more deeply on the implications and impact of such involvement.

This study aims to move the discussion further forward as it engages directly individual users and staff and tries to get at the heart of what matters. However it is acknowledged that all the research and findings, will not be totally effective unless there is commitment, resources and a change of culture. Perhaps identifying and addressing the barriers, listening to and engaging others will create the right conditions for this to happen.

QUOTES

“People should have a full say in how they live their lives and the services they need.” (*People First*, DHSS, 1990, paragraph 1.11)

“Instead of users and carers being subordinate to the wishes of service-providers, the rules will be progressively adjusted. In this way, users and carers will be enabled to exercise the same power as consumers of other services. This redressing of the balance power is the best guarantee of continuing improvement in the quality of service.” (SSI/SWSG 1991 page 9).

“We show people that we value them by keeping our agreements with them. The test for service providers now, is can users views be taken account of, no easy challenge, in these times of often shrinking budgets and increasing demands”. Kelly, Miriam. *Fair Chance*. (2002). Belfast. LEAD - NI Coalition on Learning Disability

“The views and opinions of parents, carers and their families must be central to the further development and implementation of HSS Board plans.” (Hill, Judith. (2000). *Partnership in Caring... Standards for Services*. Belfast. DHSSPS

“There is no doubt that trust, dignity and respect were seen as important features of a positive relationship between families and service providers.” Bevan, Mark. (2002) *Housing and disabled children - The art of the Possible*. Bristol. The Policy Press.

“One of the most striking issues raised by our research is the way in which various social policies fail to take account of children.” Allen, Chris, Milner, Jo and Price, Dawn. *Home is where the start is* (2002). Bristol. The Policy Press.

“Service providers need to more actively involve parents and children in the planning process and listen to their views, especially for children, who do not use conventional methods of communication.” Kelly, Berni and Monteith, Marina. (2003) *Supporting disabled children and their families in Northern Ireland*. London. National Children’s Bureau.

“The only relationship that can be seen as positive is one that is collaborative, in which there is mutual respect and a sense of partnership.” Beresford, B. (1995) *Expert Opinions*. Bristol. The Policy Press.

“Parents are experts on their child and well placed to know how services can help them to cope. By building on the knowledge and expertise of parents, and their known coping resources and strategies, services will be more effective in terms of supporting their role as a parent.” Casson, K. and Herron, M. (2000) *Enabling Activity*. Derry. Western Health and Social Services Board.

“The inquiries into Alder Hey and Bristol have highlighted the importance of patients and their families at the centre of the provision of care. Specific recommendations have been made to ensure that patients and their families are enabled to meet health care professionals as equals, recognised as the expert in the care of their child, are valued and provided with relevant information to meet their individual needs.” Department for Education and Skills & department of Health Guidance. (2003) “*Together from the Start*” Reference LEA/0067/2003

“Children and their families need to be involved at all stages of decision-making involving their care and treatment. They should be acknowledged as experts in the care of their children and should be encouraged to work in partnership with

professionals as part of the team.” Elston, Stella. (2004) *Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions*. Bristol. ACT.

“Numerous studies report the apparent failure of professionals in the social and health care systems to develop appropriate ways of working with parents.” Baldwin, Sally & Carlisle, Jane. (1994) *Social Support for Disabled Children and Their Families*. Edinburgh. Social Work Services Inspectorate. HMSO.

“Parent participation needs to be a regular and routine part of service design and delivery. This will require an organisational and cultural change in the way that services are provided. Parents need to be involved in the development of services from the planning stage to ensure that services are designed to meet their needs effectively”. (2004) *Parent Participation*. London. Contact a Family & Council for Disabled Children.

USER PERSPECTIVE

“For some time it has been recognised that service providers cannot be really effective, unless they engage those who use their services. Part of the change that is needed is for people in the community to begin to see the human face of those who provide services.

On the other side, there must be a recognition that people in the community have a certain expertise and a body of knowledge, they are professional. But what may be surprising to some people is that the professionalism in the community is not a threat to the professionalism and expertise developed within the statutory agencies.

If the attempts to develop this process of inclusion are realistic then there has to be fundamental changes also in approaches to planning. There can be no pre-set agendas – hidden or on the surface. Openness, honesty and straight talk need to guide these interactions if they are to lead to positive outcomes. One side or the other cannot dip in and out just when they feel like it or when it suits them.”

(Extract from Mc Keever, B. (2000) “Bridging the Gap”. Guildhall Press, Derry.)

User involvement is nothing new. The above extract was written seven years ago and user involvement was being discussed long before this. However there is and has been problems with this concept, primarily because it means different things to different people. Also some people do know what it means and shy away from its implications. On top of this, tokenistic approaches have often led to confusion.

Despite all the confusion, reservations and debate, in essence, user involvement means a dramatic change in the way we do things. In the retail sector we can look to Marks and Spencer. Marks and Spencer almost went to the wall because they relied heavily on expert advice to determine what products they sold. But people started voting with their feet and credit cards, they did not want these products, no matter what the experts said. Only when they listened to and responded to their customers, did their business turn around. The consumers were the experts.

WHAT IT IS ABOUT

We can get hung up in definitions, in concepts, jargon and words. So often we spend hours trying to define things without any conclusion. But it is what we understand and mean that is important,

User involvement means that those who use services should be involved in the planning and provision of services. In other words the direct experience of users should be a vital and critical component when any service is planned and in how that service is delivered. No ifs, no buts, direct involvement. It follows then if such areas are developed at a strategic level then there must also be involvement there also.

For this to happen there must be real commitment from all those involved and paths have to be created to engage and involve users in a meaningful way, in a meaningful way that suits the users too. This is really what it is about.

If organisations have a user ethos then the onus is on such organisations to engage, not the other way around. It is as much, if not more, the responsibility of those with no user background, to become user orientated.

Over the years there has been recognition in some areas that the planning and delivery of services by experts, with no engagement from those who actually use services, has often failed. The acknowledgement of the expertise of users, and the respect of where they come from can often be the first two vital steps to creative engagement.

The development of mutual respect and valuing each other can often lead to a very dynamic and inclusive partnership, radically reshaping the way things are done.

We have to be up front. If government policy or regulations dictate that organisations have to be user friendly, have user involvement, participation etc... then this needs to be stated. In other words it is not as if these particular organisations feel this is important, they may do so, but it is a government requirement.

This gives users a right to be involved and the organisation a responsibility to facilitate this. No user, under these circumstances, should feel it is a privilege to be involved.

Much has been written of how to engage users but basics such as mutual training, jargon free

user-friendly accessible language, timing of meetings, refreshments, payments, expenses, mutual respect are all areas that need to be worked out in advance and not taken for granted. Engagement, participation and involvement take effort and planning. They seldom just happen.

Those who plan and provide services must be willing to listen and to act and work with those who use services. This will take mutual trust and respect. There are many sensitive individuals from both the statutory and voluntary sectors who already realise this and put such trust and respect into practice. This must happen at all levels and not just with individuals.

However, for some people, it will take a massive cultural shift, particularly among those who work in statutory services and more particularly those in senior management. There can be no room for tokenism. Inclusion means change and a different way of doing things.”

No one is saying that users are right all the time. However when users are engaged, there must be effective listening, action and/or outcomes, even if these are not exactly what users might want. The engagement must be meaningful, it must go beyond words.

REPRESENTATION

Where is the hit list? Sometimes this is the way it seems to work. Many organisations have lists of major organisations, often linked to Equality screening and it is from these that representatives are drawn from to sit on committees etc.. With the revamping Public Appointments Process, at times this may not be the problem it once was, where there is more transparency. However this process must also be open to scrutiny to ensure users do feel comfortable with it.

In the past often smaller groups were overlooked, particularly those who actually engaged users, or indeed employed users. At times their perspective can be different from those who represent. To return to definitions, there should be an understanding of the difference.

However in all of this, what really matters is that the user perspective is put across and whoever is best placed to do this should do so, as it is not particular issues that are important, but the general thrust of the user concept. But jumping at what might seem the most articulate voice, may not be the answer.

Many times those who might have appeared the less articulate have had the greater impact, because they experience and know the issues. Training for users and training for those engaged with users, can often overcome any issues in relation to representation.

In any inclusive work we will have to determine the type of organisations, geographically where they are located, and indeed the meaning of the concepts we use. In the end, we can decide which are the most appropriate to be engaged but they still need defined anyway. Below are just some concepts and phrases that we should have an agreed meaning on and/or agreement on which to use.

- Representation - on behalf of or actually engaged inclusively with users
- Inclusiveness
- Involvement
- Integration
- Participation
- Users, service users, clients, citizens, victims, patients...
- Carers

THE OPPORTUNITY

“The expertise of families and those who work with them on the ground cannot be ignored. By using this expertise a more sensitive, caring, targeted and indeed cost-effective service could be offered to families. We have, for so long, used the correct language, developed the “in” concepts, supposedly worked in “partnership” and yet still there is so much unmet need. There is good practice in the community, it is time to learn from this. It is time to act.”

(Mc Keever, B. 2001. *Time to Act*. Guildhall Press. Derry)

Often good practice is found in different locations, in different forms and involving a variety of people. Nonetheless, there is an opportunity for all of us to learn, to develop and to send out the appropriate signals to others.

In developing a plan or strategy around user involvement, we should take a very systematic approach. The task can be straightforward. We identify organisation and groups which have a user focus, user involvement and/or involved in user issues. Through research tools, we classify

these in relation to location (geographic), to level of user involvement, discern whether they act on behalf of or are actually user involved themselves. We then have a good starting point to engage users and user organisations. Later through shared networks we can expand this work.

From these organisations we can then explore together, possible models of good practice from which lessons could be learned. The information gathered can then become a basis to create a strategic approach or template for user involvement.

We have had so many reports, consultations and discussions. This is a real opportunity through inclusive practice to actually make user involvement work effectively in a general way and not just in the models of good practice. It also has to be highlighted that some statutory organisations and groupings have developed models of good practice in relation to user involvement issues.

USER INVOLVEMENT IN PRACTICE

“Some people pursue “user involvement” as a goal in itself whereas often good models of practice emerge as a result of “user involvement” as a process towards a different goal. As a concept, during the many years I have been involved in this campaign, I have seldom heard anyone within the campaign refer to the term “user involvement” as a theory.

To put it more simply, the developing of relationships and trust, the recognition that each person had something to bring to this, the valuing of people, respecting difference while still being able to challenge – these were what was important. It was these that built the core ethos, which kept us going in those dark days when there seemed no hope, no outcomes.

But also, and this is very important, this atmosphere facilitated the equal valuing of someone who licked a stamp on a letter to an MP alongside someone who made a presentation. The person or organisation there from the beginning had no priority over someone coming late to the campaign.

This ethos of mutual respect ensured that as far as possible information was accessible, because that is what most people wanted, and always any business was grounded on sensitivity to parents and disabled children.”

(Mc Keever, B. 2006. Making the Impossible Possible. Guildhall Press. Derry)

In the Homes Fit For Children housing campaign (referred to above), the ethos and underpinning values relating to user involvement evolved along with the practicalities of such involvement. It takes both. In practice the model of user involvement that emerged through this campaign, helped change government policy in NI, England and Wales.

As a result families of disabled children now have a better quality of life in housing provision, since the means test on parents of disabled children was abolished. Those families in private housing have easier access to the housing grant for adaptations (Disabled Facilities Grant) for their children as a result of the partnership working during this campaign.

SUMMARY

In essence, the development of a practical template on user involvement is a starting point. Developing a culture of mutual respect, acknowledging experience and commitment to user involvement is critical alongside this template.

In addition there should be a clear understanding of why user involvement is important to the host organisation as well as what is expected, what the organisation does (concise, clear accessible language) and what this means for the user.

If all this is in place, then positive outcomes from inclusion can be expected which will benefit everyone. Positive outcomes, even though they may not satisfy everyone, are necessary to sustain user involvement.

User involvement can work if we work at it. If we are willing to identify the barriers and then overcome them. It has been about too long to ignore, now is the time to actually put it into practice.

In ten years of work involving parents of disabled children, I have written extensively on user involvement issues. The emphasis is that user

involvement must not be tokenistic (1), it must reflect the lived experience of those who use services (3) in real partnership working with those who plan and deliver services.

It is about mutual respect, valuing people (4), action (2), results, feedback and most importantly about being listened to and heard (5). It is less about representation or definitions, for the sake of definitions (2). Although change can be slow, real change is possible as individual voices come together (6). It is not new.

It is simply about having a voice, when no one seems to listen to you, a voice that can change your world and maybe even the world around you (6).

There is very little that is new about the concept of user involvement, only that different people are experiencing it for the first time and also there are different interpretations of its meaning. With such a wealth of experience from a variety of sources, it now seems appropriate, after all this time, it is time to address this issue with the vigour it deserves.

1 Mc Keever, B. (2000) "Bridging the Gap". Guildhall Press, Derry

2 Mc Keever, B. 2002. Beyond Words. Guildhall Press. Derry

3 Mc Keever, B. 2001. Time to Act. Guildhall Press. Derry

4 Mc Keever, B. 2006. Making the Impossible Possible. Guildhall Press. Derry

5 Mc Keever, B. (2000). Listening to Parents – parents as professionals.. Guildhall Press. Derry.

6 Mc Keever, B. (2001). In the Telling. Guildhall Press. Derry.

CONCLUSION

It is acknowledged that there is a certain re-search/consultation fatigue among users. With the Review of Public Administration, many staff in statutory services has been frustrated over uncertainties and possible job losses. In the voluntary sector there continues to be uncertainty over funding, which exasperates workers employed in these groups. Many in this sector are focused on maintaining their work and securing funding.

Against such a pessimistic back drop, it may seem that user involvement has no chance of developing. The reality is that this pessimistic picture can be challenged by an honest open approach to issues. Not promising a resolution to these issues, rather collating evidence, particularly from users and challenging perceptions.

The voices of those most affected by user involvement have to be listened to, have to be heard and have to be acted upon. Guidance, policy, strategies and legislation are not enough. We need to identify barriers, to look at the issues, to be challenged and through partnership working start to address these. Many have already shown us how this can be done.

If we really do value each other and we are convinced that user involvement does enhance the quality of services, then we will find ways to make it work. In true partnership, we can all find a positive way forward.

What seems to be emerging is that there are distinct elements involved when discussing inclusion and user involvement. Sometimes organisations focus on the practical ones while overlooking the core ones that actually change the way work is done. Both elements need to be addressed if user involvement is to become reality and move away from tokenism. However all the practicalities will not lead to true inclusion or user involvement, even though perceptions may indicate they do.

It is so easy to state that meetings are strategically planned to accommodate users, that there are refreshments, and expenses are all paid but a lack of understanding of the meaning of user involvement may mean what is created is simply a talking shop with no significance.

Advance preparations are necessary, commitment to user involvement is essential and an understanding of who does what and what is

expected is critical, as the compost on which the potential of user involvement can take seed.

User involvement should never be mistaken as one sided, as it often is. It is not about fitting users into existing structures. Rather it is a mutual relationship which should be beneficial to all involved. The experience and knowledge of users and service providers, brought together in a mutually acknowledged respectful way, so that high quality services are delivered by a sensitive caring workforce which is inclusively guided, monitored and trained. Everything must change.

User involvement can be measured in outcomes. It also can be marked against a template of options, if you like a tick box, and the degree of user involvement can also be gauged. Sometimes simply asking users who are involved, key questions, can give a good indication of the level of user involvement. But practicalities are only part of the picture. When decisions are made on criteria, there needs to be some discussion on developing a measuring tool that is effective. Monitoring and evaluation of user involvement are critical if such involvement and participation is to be effective.

APPENDIX 1

“User Involvement – an Inside View”

A presentation by the Family Information Group, into user involvement issues, from the user perspective.

The Family Information Group raises issues that impact families of disabled children. The Group is user led and comprises of past and current parents and relatives of disabled children. It was founded in 1997 and has produced publications, leaflets, DVDs, reports and research into issues affecting families of disabled children.

It has provided training and awareness sessions on “the family view of disability” and user involvement issues extensively throughout Northern Ireland to diverse audiences including: social workers, social work students, community workers, early year staff, students in secondary schools and colleges. Parents, Health and Social Care management, hospital staff, health visitors, physiotherapists, speech and language therapists, dentists, occupational therapists, housing officials etc....

Aim of Session

To give participants an insight, from a user perspective, of user involvement issues as lived and experienced by users.

Objectives

- Briefly explore legislation and current policy which directly or indirectly impacts on user involvement issues
- Analyse different views and perceptions of user involvement
- Discuss issues around what makes a user (Case Study)
- Consider the nature of partnership working with users and staff and if this can make a difference (DVD Case Study)
- Challenging the roles of professionals and users
- Looking at inclusive practice - theoretical myth or practical reality?
- Making it work - inclusiveness in practice (DVD Case Study)

Background

Equality Requirements (Section 75), Disability and Carers Legislation, the Children's Order/Act and other laws and policy identify the need for inclusion and for marginalised individual and groups to be listened to, heard and their needs to be addressed.

In Northern Ireland recently DHSSPS have set out guidelines on user involvement, which they have called Personal and Public Involvement (PPI). These will eventually apply to all Health and Social Care agencies and will possibly become a statutory requirement of all those who work within these agencies.

In other words, user involvement will no longer be a choice or option, but a necessity, a requirement for all staff and management. Staff will be expected to work inclusively with users, users who have been living user involvement for many years (even though they may not have known this). The very fact that they are users means they are involved but this has not always been inclusive or in a positive way.

It is acknowledged that these Guidelines will take a change of culture in some paces, time,

resources and positive support, to become a reality. They will take real partnership working.

This workshop takes participants on a journey. This is a real journey (through case studies and DVDs) into the reality of a user. In that journey there are opportunities to see, discuss and question some of the key concepts in user involvement from a very practical viewpoint. It is primarily focused on attitudes, on raising awareness, of telling it as it is, of challenging and analysing current practice.

There is a general understanding that many of those professionals who work on the ground with users are positive, supportive and often very much tuned into the issues that affect them.

However if we are to be inclusive, if we are to address some of the negative attitudes and perceptions of users, if we are to work within the law, then a better understanding of user issues is needed, this session will help in this. It will not give all the answers, but it will take participants on a journey that hopefully will help them when they engage with users.

The Session

This session is primarily based on the user view of user involvement. This view comes mainly from the work of the Family Information Group and the parents of disabled children who have been involved with the Group. It is only one view, it may not always necessarily be what could be termed the “right” view, but it is a valid view that is often ignored. This perspective is based not only on the experience of individual parents, but on research findings and also feedback from many of those who work with families. However other views will also be featured and participants will be encouraged to share their views and experiences. User involvement crosses all areas of care provision.

Structure

Each session will be led by a Facilitator, usually someone who has direct experience of user issues. Participants will be encouraged to take part, to involve themselves in discussions and to ask questions. It is hoped that the session will be informal, but with participants respecting those around them while adhering to a strict code of confidentiality. The success of the session will often depend on the level of engagement of the participants.

Method

The session involves specific presentations on certain themes. Time will be allowed for discussion as well as question and answers. It is important that participants try and relate some of this information to their own settings. Video/DVD are used to illustrate key messages. At the end of the session information will be given to the participants to enable them to have free access to Family Information Group publications on the Group's website. These explore some of the issues in more depth. Also signposts will be given to other organisations that can offer help and/or information. Each session ends with participants completing their own evaluation of the event.

Topics (Dependant on time available)

What is a user? (Case Study)

User Involvement – what it means to professionals

Barriers to user involvement and opportunities for involvement

Positive change through user involvement (DVD)

Professionalism of Parents - acknowledging the expertise of parents

Inclusion – what does it mean? (DVD)

Legislation, Policy and Guidelines

Partnership working - does it work?

Valuing participants' experiences - recognising that many people already have skills they need when working with users

The Way Forward

Proposed Learning Outcomes - Understanding of:

The main issues in relation to user involvement

The relevance of legislation and policy

Difference between tokenism, partial involvement and inclusion

The different roles of professionals involved with users

The user view - what does this mean?

Barriers to and opportunities for user involvement

Possibility of real change through partnership working

APPENDIX 2

Legislation

The Housing Executive Act (NI) 1971

The Chronically Sick and Disabled Persons NI Act 1978

United Nations Convention on the Rights of the Child 1985

The Education and Libraries (NI) Orders 1986 and 1987

The Disabled Persons (NI) Act 1989

The Children (NI) Order 1995

The Disability Discrimination Act 1995

The Carers (Recognition and Services) Act 1995

The Education (NI) Order 1996

The Code of Practice on the Identification and Assessment of Special Educational Need 1998

Section 75 of the Northern Ireland Act 1998

The Carers and Disabled Children Act 2000

The Carers and Direct Payments (NI) Act 2002

The Carers (Equal Opportunities) Act 2004

SENDO – Special Educational Needs and
Disability Order 2006

The Disability Discrimination (NI) Order 2006

Section 49A and 49B of The Disability
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APPENDIX 3

Essential Reading

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Summary of Public Inquiry Recommendations from:

Alder Hey (2000)

Victoria Climbié (2003)

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Donaldson and Foster (2006)

Overview of main legislation in relation to children, carers, disability and equality issues - see below.

APPENDIX 4

Background Reading

Below are additional references to user issues that should inform and expand the discussion in relation to user involvement.

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