



Direct Dial No: 01463 723557

EXPLORING THE WAYS FORWARD FOR SERVICE USER INVOLVED RESEARCH – VALUING PEOPLE AS EXPERTS IN THEIR OWN LIVES EVENT.

UNIVERSITY OF STIRLING

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HELLO my name is Graham Morgan. I work with the Highland users group which has a base in Inverness and a network of members spread across the Highlands.

It feels very strange to call what we do in HUG “research”. I have always been at pains to say that the numerous reports we produce are not research but are instead a way of finding out our members views on a number of issues that affect them. They are our way of finding out the intelligence that our network provides about the lives we lead and they are our way of getting suggestions about what it is that would improve life for all of us. By getting this intelligence and distilling it into a report containing the numerous diverse views of our members we produce a sort of policy document that anyone can use to improve life for those of us affected by mental illness.

It is also very strange to be talking about research to lots of people and hoping to make it interesting. I would like to think that our reports are interesting but I have severe doubts that people sit up discussing them in a passionate haze of drink or lie awake at night thinking about just what was meant on page 6 paragraph 3. and I am sad to say that I cannot think of someones stomach clenching with the power of what we say about incapacity benefit or stopping stigma in the workplace.

HUG is a project of:  Highland Community Care Forum
the voice of users and carers

Highland House 20 Longman Road, Inverness IV1 1RY. Tel: 01463 718817 Fax: 01463 718818. E-mail: hug@hccf.org.uk

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Reports just aren't like that, they seem like some sort of objective way of distilling a communities views on particular subjects and yet maybe they should be, maybe they should contain that passion.

Tomorrow I go along to the police headquarters in Inverness to discuss our report on the way they treat us. Its filled with quotes and as I write I see that their power is diminished; I just remember this wonderful person telling me about the police standing around her as blood poured from her and saying "I'm not touching that" and you wonder at the callous inhuman brutality of a public servant. Then there are the notes of huge gratitude from those that have literally had their lives saved by the police when it seemed that everyone was neglecting them at their time of greatest fear and anguish and lastly, that I can remember, the profound relief at the sensitivity about the police who witness us in a state and instead of arresting us take us home, settle us down and give us a break and peace. And as I think of these words, these experiences I worry about the way I write about what we go through. Give me a piece of paper or better yet a computer and sit me down to write about our members experiences and in some ways I could make the paper glow with the power of the extremes. Just let me write from memory and the freedom to say anything and life could be so real and yet it isn't really in our reports and I wonder why.

A Hug meeting that leads to a report is usually so invigorating, we talk and talk and discuss and share and reveal and someone will get all passionate and not stop talking, another person will disagree with what someone is saying and say so vocally and then we will pause to remind each other that we all have a right to all our views but that we need to respect this difference. Then someone will say something so shocking that all our voices go gentle and another one will say startlingly clever things that we have to check out because we don't quite understand what has been said and a new member will look on with bewilderment and then someone gets it all mixed up and says something that has nothing to do with anything and it will be reinterpreted or moved on and at the end we're saying "well that was good" sort of panting as if at the end of a bracing winters walk, ready to say our goodbyes and "see you next time" and "keep up the good work" and "that was well said" and "by the way what about this and this" and "do you want a last coffee" and then in the car its time to witter before calming down. So with that, with that wonderful conversation and information why don't our reports shine with the vibrancy of our membership.

Maybe its time to go back to the beginning. We decide on a report at the beginning of the New Year when our committee meets. At this meeting we think about what are the key issues facing our members? What are the new changes in policy? What is likely to be an important topic in the future? and what haven't we raised for some time? and from that we end up with a year long list of discussion topics that we are sure will exercise our membership. It's not a set list, sometimes life changes quickly and we need to respond to the views of our grassroots

membership immediately and it is at these times that we get a high turn out at our meetings. So far the biggest turn out being of over 130 when our drop in and employment services seemed at risk.

Having decided on a topic it all becomes very routine. A few weeks before the meeting is held a poster is sent to each branch of hug inviting people to the meeting and advertising it, if appropriate, at the venue, such as a drop in centre or hospital. Then we hold our meeting offering to pay expenses to anyone who needs them but because we hold meetings locally no one ever really claims anything. Before the meeting, usually in great haste, I will scribble off a few pages of what I call prompt questions. I find that unless we have specific questions people can dry up quite quickly. The questions are purely written as a way of getting people to talk and are designed to encourage as much debate and conversation as possible. Usually it is easy to decide on the questions as we already have a lot of knowledge of the subject but sometimes we ask hug members to help design the questions or people from partner organisations who already have an interest in what we are talking about.

Then it's the meeting itself . we usually have a lot of people who are well used to how a meeting is run but if necessary or there are new people there we may discuss the subject and the fact that everyone has a right to say anything they would like on the subject, that all opinions are valid, that we want everyone to contribute and that there are groundrules to make this happen.

Then it's up to me to make it as comfortable as possible and that everyone who wants to has a chance to speak. I take notes at the same time which rapidly degenerate into a hard to read scrawl but it is better than hoping that someone will take notes that make sense to me though sometimes two of us do this. Ideally there would be loads of time and resources and we would record each session and transcribe it and spend ages writing it up but we never do so instead I write up every meeting and then try to distil the hundred odd pages into a short concise and readable report. It's really a bit like a jigsaw puzzle, I trawl through the minutes highlighting each point and quote then transfer the quotes and issues into the main report until we have all the points our members raised covered. Initially everything is a mass of quotes as I love putting down peoples own words so much but then quote after quote is wearying so they get whittled down and the narrative that illustrates the points people were making increases. I really strongly believe that our reports should be the voice of our members so I do as little interpretation as possible and confine myself to making only the suggestions and recommendations our members have made. It seems to me that I have lots of opportunities to speak out but here the task is crucially about giving voice to our members not being my own voice. My words are there just to say what has been said by a group of people as accessibly and clearly as possible and with that it is easy to lose the opportunity to give free reign to the power that words have to stir minds and move souls with the urgency of what we wish to achieve. Perhaps as I

write it would be good to turn those words of passion into a document of passion where you look at what everyone has said and almost turn it into an essay where you use your own voice to enhance and embellish and make real the lives and views of our members, almost to turn it into an artwork that can really make the need for change real. But it does feel that somehow this is wrong that if I use the power of my feelings I subvert the direct testimony of our members and turn it into my voice and my story and so for the moment maybe it is true that the text of a report needs to remain slightly clinical almost approaching the academic and maybe just maybe that is good because the power of our reports may be that they convince that we really have canvassed our members views, that we have taken a step back so that everyone knows that it is their voice not the voice of a radical few determined to be as outspoken as possible. When we demonstrate that we routinely involve more than a hundred people in an exercise like this we make it crystal clear that what we do at least carries an element of authenticity, respectability and accountability to our readership and membership.

That certainly seems to be the effect. By demonstrating our determination to represent the diverse views of our members, by writing our members views clearly and unambiguously we make it obvious that we base everything on experience and grass roots opinion. No one can deny the validity of our members experience and no one can deny the power of their opinions. They can disagree and refuse to act and all these frustrating things but really they can't say that what we say isn't true to our memberships views.

It is maybe because of this that our reports are so successful , yes they can be accused of a lack of methodology and expertise, none of us are trained in research, none of us have the time to be academic with what we do, we do not have the resources or the skills or the people to make sure that each consultation truly represents our community and the diverse elements that make up that community, we're not sure that we don't lead with our questions or that the way it is all written doesn't produce its own answer. We don't know if the creation of a report is distorted by the values of its author, whether the use of quotes is done to shock or illustrate whether a minority view is given as much weight as the majority one just by virtue of the number of words used. But we do know that in some way what we write represents a slice of the lives and experiences and aspirations of our membership and that it has had an effect.

And what is the effect of our reports there is not much point in writing these things if they do nothing but create cleared forest and unheard words. The lovely thing is that each and every one of our reports has had an effect in one way or another.

It feels like in the early years every report had a tangible outcome. The very first one on the siting of our new psychiatric hospital was quoted as determining the final outcome of where New Craigs was built and catapulted us into involvement in its design, naming and the selection of builders. Our report on suicide ultimately

helped gain a liaison cpm service for Raigmore. Our employment one helped establish an employment project. Our ward rounds one stimulated a working group to look at how ward rounds are conducted and inspired follow on research by other people ten years later. Our medication one helped prompt the additional provision of support and information from an extra chemist in our hospital.

Sometimes things are less tangible, our reports on out of hours services, crisis services places of safety and so on initially had no effect and yet they inspired the provision of funding to stop the use of police stations for people in crisis and the existence of ways of providing safe places for such eventualities, they contributed to the general acceptance we have in the highlands that out of hours and weekend support is vital that safehouses are highly desirable when in the early years people could only get as far as saying that providing a service out of normal Monday to Friday 9-5 times would only make users more and more dependant.

In later years our reports have had less of an immediate affect on services and more of an effect on policy and debate although we remain convinced that our reports both on drop in services and tag our employment project have helped both services look for extra funding, given more security and helped with internal reviews.

However policy; our report on young people was said by the professional lead for primary mental health services to be an excellent report, "very reassuring and helpful" and was presented to the committee for children and young people where the testimony of one of our young members provided the reality behind the report that caused such vigorously appreciative views from our councillors and officials.

Our report on spirituality was said by our director of community care for NHS Highland to be "fascinating, insightful and informative" and by the Scottish Inter faith council as "an excellent resource that should be used to inform the health service of your needs." Our second report on medication had the following reaction " this is an excellent piece of work which your organisation can feel proud to have produced. It will be used to inform the development of these services." That was the acting chief pharmacist for primary care in Highland.

To wind up with the effect our research into our members views has I'll finish with two reports we wrote; a report on psychiatrists at the request of psychiatrists that initially turned out so potentially negative that we had to find some positive stories for the appendix to steer some way from the general gloom. This report was featured in the bulletin on the Royal College of psychiatrists turned into some reference material for an archive that can be accessed by millions of academics, was written about in a number of magazines including open mind magazine, was included as reference material in Dorothy Rowes latest version of her book 'beyond fear' and prompted awareness training of around 70 psychiatrists.

The last but one report was on physical health. We had some lovely comments locally and had it sent to the editorial group of the Royal college of psychiatrists as “a brilliant” resource for some similar work they were doing . It was also placed on their website, used to train sports students at Gloucester university. It was referenced by the Scottish government in their own publication on the same subject. It was used by a mental health team in New South Wales, distributed by e.mail by the international initiative in mental health leadership and highlighted in the E.newsletter of the center of mental health research run by the US federal governments department of substance abuse and mental health.

So reports have an effect. We have produced around 50 so far and tend to get to produce about 5 or 6 a year. Each one has produced some sort of positive effect. I am told that our reports are research; they are research carried out and led by users with users. They may be very broad research but they give us credibility and ensure that our voice is heard, that the passion of our cause is listened to and that the changes we yearn for eventually have a chance of happening. So for those that are interested I would have no hesitation in encouraging users into research. If we can do it ethically, credibly and effectively we lay our own plate of change ready for serving and enriching the lives of our fellow users and friends.

Thank you