

# User Carer Involvement (UCI), John Robertson

Good afternoon ladies and gentlemen and thank you for joining us today- my name is John Robertson and I work – on a part time basis with a small charity in Dumfries and Galloway called User and carer Involvement.

Time does not permit me to expand too much on the role of UCI but our mission statement covers the key headings Mental health, Dementia and Learning Disabilities – we are a small team of three with admin support and it is worthwhile commenting, at this stage, that our task would be impossible without a commitment to the theme United We Stand both from the staff viewpoint and that of the extended workforce of volunteers that we rely so much upon for support and input.

The theme United We Stand carries with it an implication just as the saying goes – united we stand divided we fall ... perhaps that is just too strong ... too pessimistic, but this could provide an excellent starting point for further discussion...

I have chosen three of our projects today to illustrate how we in UCI have subscribed to todays theme and hopefully in doing so underline how important working together is in making a difference.

## **Dementia Champions ...**

- Dementia Champions – is a unique and innovative approach to the dementia challenge in Dumfries and Galloway taking on the challenge faced by each general hospital health staff member when someone with dementia comes into their care with some other physical illness or injury not necessarily related to dementia.
- Some five years ago one of the Alzheimer Scotland carer support groups in Lockerbie identified an issue of common concern amongst its members where each of them – all carers for someone with dementia – had experienced disturbing levels of inadequate care for the person they had looked after whilst

they were in the care of the local hospital – due, in their view, to an apparent lack of understanding/knowledge of dementia, and that this also extended to themselves as carers, where again, there seemed to be a worrying lack of appreciation of the carers role and knowledge with regard to the patient involved. Several had gone through the hospital complaints procedure but had found this to be both impersonal and unsatisfactory in its response or resolution of the problem ... with no sense that the necessary changes would be introduced.

- The Alzheimer group leader suggested at this stage that UCI become involved and following several meetings with the carers involved listening to their concerns and thoughts on the way forward it was agreed that their combined experiences should be employed to put together a case study for presentation to senior staff in NHS Dumfries.
- To drive this proposal further forward one of the Nursing Directors was invited to meet with the group and following this very effective meeting the written case was presented and very quickly action taken ... with agreement that a meeting would be set up involving the NHS, UCI, Alzheimer Lockerbie, and the University of West of Scotland to discuss the prospect of establishing a unique pilot training programme for (initially) senior ward staff.
- The course title was agreed as Dementia Champions to reflect the key aim that the nurses involved would lead by example and become, where possible, mentors to other junior members of staff.
- The first year drew in approximately 20 new recruits and the course of study was programmed over a 10 month period with one of the training days given over completely to carers input. This carer input element of the course has been rewarding for everyone involved – carers, staff and students and has been reported on by staff and students as a turning point in their understanding and appreciation of what dementia is about. The course is now just about to enter its third year with thirty Dementia Champions trained so far and a further thirty enrolled for 2010 including OT`s, Physio-therapists, District Nurses and

Nursing Assistants ... what a difference from the despondency and sense of powerlessness expressed in those discussions of some five years ago in Lockerbie!!

- The programme continues and carers are still closely involved not only in the training but also in the ongoing review and evaluation of the course.
- A very practical example of where the united voice – given support – can make a real and very positive difference.

### **New Build Psychiatric Hospital ...**

- Cynics will comment that this is just the NHS complying with national guidelines, that they have no choice in the matter if they want to progress their ideas and business objectives, and in some cases, and with some people, I have no doubt that there will be some truth in this but with regard to this specific project I can report, with some confidence, that there has been a real effort made to be as inclusive as is practical and possible within the time frame provided and the resources available. The second phase of the programme launched in Feb 2009 .... and the benefits for all involved have been both tangible and productive.
- But this project goes back as far as 2004 – so it has been running now for five years and will continue to run until the official opening sometime early in 2012 – eight years in total and with user/carers input/involvement from the very beginning. From initial consultation through to the submission of the Final Business Case - from theory to reality and everything that this has involved along the way.
- The tangible benefits for everyone involved have included a growing sense of team work across the professions and including the voluntary sector – again common cause generating a sense of commitment and improved joint working practice; there has also been a real and oft times surprising quality of input and appreciation of the complex issues involved from every quarter and as a result of this we have

seen ideas develop and the ownership of the project grow at every level.

- The involvement process has included a series of open workshop meetings across the region starting with a launch at the beginning of the year for everyone involved and then three sessions March, June and now November with four geographically located meetings in each session – firstly to discuss user/carer ideas and concerns - secondly to feedback on the progress being made (checks and balances) and finally to present the recommendations that are being submitted to the planning authority for approval ... with hopefully a high degree of ownership as those involved can see that their recommendations and ideas have been listened to and incorporated where possible and where they have not - that a considered explanation is made available.
- The key lesson learned for UCI is the need for a wide and dedicated range of people able to commit to something like this – if not then the downside is that too much pressure is placed on too few people – and this is something that we are working on with our regional involvement groups.

### **Regional Involvement Groups ...**

- Dumfries and Galloway is a large region – some 2,400 square miles stretching from Langholm (almost in the borders over to Stranraer on the west coast some 120 miles as the crow flies and almost the equivalent of the distance between Inverness and Dundee and the same travelling time. Traditionally carer/service user involvement has all too often come from Dumfries and its satellite towns with little or no voice for people who live in the more remote parts of the region – particularly in the west and yet we know that the user/carer experience of NHS and Social Service provision varies enormously dependent on where you live in this large rural part of Scotland.
- UCI along with Alzheimer Scotland believed fervently that this had to be put to right and for the last year we have been working together to set up a network of small Involvement Groups, for carers in the first instance, in each of five regional

areas – Dumfries, Stewartry, Wigtonshire (Newton Stewart and Stranraer and finally Annan and Eskdale.

- We currently have groups in Dumfries and the Stewartry and we are about to start our first Wigtonshire groups in November. It is still early days but we have already been able to make our voice heard in each of the projects previously covered and there are a number of development ideas currently under review. The most important feature of this being the growing sense that individuals can make a difference when their voices are united by common cause.
- New members join each month as word spreads regarding the concept and of course each new member brings with them a new story and a new and fresh set of skills and experiences. They find encouragement and support from the current members and in return they instill fresh energy into our existing membership ... a reminder, if it were needed, that although we are making a difference and that things continue to improve there is still much to be done and that there is certainly no room for complacency.
- And the key to ongoing development of these groups ... ? well there is no doubt that right at the top of the list will be the strength that each and every member gains from being a contributor to the united voice that the group offers.

Many thanks for listening and I would like to finish with a short film – a television advert many of you may remember – the Unison recruitment advertisement of several years ago? - which given the theme of this event seemed very appropriate ... I hope you enjoy.

### **Short Film: The Polar bear and Ants**