

### **Original Message**

**Sent:** Tuesday, June 24, 2003 10:46 AM

**Subject:** user involvement.

Dear Rogan,

I work as co-ordinator for mental health User forums in Coromondell.

We are hurtling towards Integration so by October we should have a Health and Social care Trust. At the moment they are putting together the constitution for the Commissioning structures. My enquiry centres itself around the composition of the proposed Commissioning Board.

We are advised that although User reps can attend and "influence " the decision making processes of the board they are not entitled to formal voting rights. Of course we are challenging this but have no info as to whether they are right to say what they are.

Do you know or is there someone else who could advise us on this issue.? Obviously it is such an important issue for us in Coromondell as without voting rights we are left again at the mercy of other peoples value bases and sensitivity re User involvement.

With Best Wishes Launcelot Andrews.

### **Reply**

**Sent:** Monday, June 30, 2003 13.48 PM

**Subject:** user involvement.

Hello Launcelot,

Thanks for the contact.

I don't know whether the Commissioning Board advice is right or not. MIND has a legal unit, of course...

I'm wary of just gassing here, especially as I'm unlikely to come up with anything new to you, and you may simply disagree anyway.

But I do want to throw out the following line of thought to see what you think. It ends with the suggestion that somehow this problem is not quite the issue and/or could be framed some other way.

I was in a user recruitment panel recently. We were involved in interviewing a policy development manager for the local Trust. She was young, bright and fervent about improving standards. I noticed she'd taken a counselling course during her training history and asked her about it. She said she'd realised that her role now must involve consulting with service users a great deal. And doing that needs sensitive and skilful listening. So she went on the course to learn how to listen. I was highly impressed.

I have always taken the line that managers should come to users, rather than expect users to come to managers - both literally and as a principle. So that real listening can take place. And listening means real contact, real human inter-action, a quality thing, the more sensitive and skilful the better. There's nothing patronising about that, in my view. It's quite obvious, a better quality of listening is needed everywhere. Of course there are the individuals in the user movement who can remain effective and relatively unscathed in the business meeting kind of environment. And there's training and preparation and mutual support and all that stuff. But still and increasingly, I believe that for users to join your average business style meeting is an acceptance of a plain denial of reality, a denial of real listening, that is almost collusive.

It's not just mental health. Almost everyone who has to resort to healthcare services in some big way or other has experienced, in the process, pain, distress, fear, loss, loneliness, incoherence, imbalance, a blow to security, to sense of self - all that and more. I want to ask all managers as they come to my door desperately keen to consult, would they be willing to go back in mind to the very worst experience they personally have ever had, and then imagine talking from within that experience to a rushed business meeting composed of 15 people they hardly know? Is that consulting? Involvement?

My conclusion now is that the approach still current - that consultation is a matter of inviting user reps onto committees, boards and business meetings - is not just careless practice, it constitutes the functioning of a mass denial mechanism. It is a pathological denial of the fact that consultation starts with making sympathetic contact with human pain, dislocation and vulnerability and it constitutes a refusal to enter that difficult process. No, you join us where we sit in our castles and round our tables, whirring frantically like helicopters - we certainly will not be joining you. Things get out of hand in *your* neck of the woods, pain exists there, and we might lose control.....

I remember a close friend of mine now dead from cancer of the bone marrow. He was in hospital receiving very good and careful high tech treatment, being monitored minutely for the slightest shift in blood composition and so on, with young and very clever people using the latest technology to try and save or at least prolong his life. And he raged and wept with me. He knew it was good treatment and was grateful for it. But at all times he felt like an *object* in receipt of all this help, he said. At 2.00 in the morning, facing his death, he the *subject* in the midst of all of this, the I, the self, felt an appalling desolation. He knew about our ward round code campaign. He said that the other day he had told a young doctor he had a list of questions he needed to ask urgently. The young doctor, last out of the door after the ward round, said - but you could have asked the consultant those questions just now, this was your chance. My friend said, these are questions of enormous importance to me, they concern my life and my death, my heart is in my mouth and is soon to stop and I cannot be sharing my trouble with a circle of strangers, none of whom have even been introduced to me! Do you want a counsellor, then? asked the doctor. Which again was wrong. You cannot put ordinary things like pain and death in a little box and call it counselling. The young man was trying to help but never came near.

I do not think I'm digressing here. Healthcare high tech leaves out the human being and in a way defends the Healthcare technician from being awake to the patient's difficult human reality. I think we all find pain hard to deal with, including and maybe especially those who work in the care services (who are dealing with pain all day). It is human nature. I think many aspects of the medical model and also of the management model and also the example of inviting users into business meetings, and maybe even the very design of business meetings themselves, are ways of objectifying and staying cut off from pain, even while the addressing of pain can be said to be the *raison-d'être* of all the care services.

So do the Coromondell users really *want* to be on the Commissioning Board?

Of course there's the need for real influence, solidly established. But is that the same thing as having one or two or even three users on the Board, proudly waving their votes, confronting those mountains of paperwork, so easily defeated? And what if someone takes the Board to Court?

It's all very well to carp and I still haven't come to clear ideas of my own here. My own preference would be for the Board to be required formally to answer and publically respond to user concerns and suggestions, as proposed through consultation channels of the users' own choosing. And I would recommend those channels should include leisurely user gatherings, carefully planned and skillfully led, addressing issues that concern them, rather than endlessly just responding to the service agenda.

Another little thought I've had, going back to the user interview panel. (The alternative model here is of course to have one or two users on the main panel. But these again are just a minority vote, looking to the service chair for the lead, just as on the Commissioning Board).

The user *panel* interviews candidates specifically on certain aspects of the person spec., above all the core relationship skills item, an attribute marked as essential. The panel win sufficient credibility for themselves over time to become accepted as the best possible tool for judging candidates in this

area. If they recommend that someone has failed to meet the core skills criterion, that person will not get the job. In other words the user influence is given a genuine weighting within its strongest area of expertise, conditional on certain demonstrable things, ie training and so on.

Is this a clue as far as your Commissioning Board is concerned ? That certain areas of the Board's concern and/or activity are agreed beforehand as being the particular preserve of the user voice and experience. Some sort of influence weighting is previously agreed for those areas, stronger than just a few votes, perhaps actually giving the user perspective some jurisdiction. And that will spare users ploughing through all that other detail which in most cases is not their area of expertise and need not be and in my experience merely bewilders and depresses.

So there you have it. That's the best I can offer.

Before I go, I'd like to mention a list of principles I've recently come across. They were given out at a MIND training day and are by Jim Read who ran the day.....

All the best

Rogan Wolf