

Partnership boards must make more effort to consult people with communication difficulties

Partnership boards pay lip service to consulting vulnerable people. In the second of his series of articles on communication, Tony Bamforth talked to John Burley whose work in Leeds is showing how proper consultation should be done.

'Nothing About Us Without Us' was the key principle enshrined in Valuing People. Why is it then that the vast majority of partnership boards still have not managed to develop meaningful, regular and consistent methods to canvass the views of the most vulnerable of those people we label as having learning difficulties? Partnership boards can make a real difference, just by taking time and making an effort to develop inclusive methods of consultation.

John Burley is user involvement officer at Leeds Partnership NHS Foundation Trust which last year won the good practice award from Valuing People for their innovative consultation methods. John told me about their approach. "Our work operates on two distinct yet complementary levels: individual and group. Work with individuals involves the use of objects of reference, intensive interaction work. Work with groups has developed into what we call 'inclusive consultation'".

Inclusive consultation originated when they started to think about the quality of participation from service users in the local partnership board reference group (a service user group which reports back to the partnership board). At that time, the group involved mainly people with lower needs. "We realised that the people most reliant on services – those with higher needs and communication difficulties – weren't attending and having their say – in effect, these key stakeholders were not being represented at all!"

To overcome this they developed new pioneering ways of working with people with learning and communication difficulties in a group setting. They involved a local advocacy project from the start, speech and language therapists, communication workers, as well as intensive interaction facilitators. One of the main points stressed in research by RNIB with the Norah Fry Research Centre (Information for All, RNIB, 2007) is that 'people with high individual communication needs often rely on others to interpret their wants and needs', as well as for example, holding more complex information they may need to access services. Therefore, the people who are closest to the individual, such as key workers, carers, family members, ought to be viewed as a key resource, to enable meaningful communication between the individual and the partnership board. Information for All provides an excellent summary of the range of needs among people who have learning and communication difficulties. Step by step instructions are provided to help make communication as fruitful and mutually rewarding as possible.

John and the team who developed the inclusive consultation model in Leeds recognised this early on and made special provisions. "We invite the person with learning and communication difficulties together with the person with whom they are closest to the group", he said. "This person plays the role of an advocate, ensuring the person they support is enabled to interact with others in the group as much as possible. The aim is to create the structure and provide the facilities for this to happen and to ensure as much participation as possible".

To avoid the views of parents or carers being mistaken for those of the people themselves, John advised that answers or suggestions were 'colour-coded' to indicate whether information came from service users directly or the people supporting them. How had they managed to cater for the wide variety of communication needs presented by service users?

John explained that to do this in one large group would be time consuming and monotonous. They decided to run three different groups focusing on different methods of communication. Participants then had a choice of joining different groups according to their individual preference and/or abilities:

1. The Discussion Group – for people able to communicate verbally and in writing.
2. The Signs and Symbols group – for people whose preferred way of communicating was not by language or words alone but still involved formal shared communication methods
3. The Supported Group – for people with individual or 'informal' methods of communication where an advocate would attend with them to interpret their needs and wishes for the facilitator.

The next stage in the process was to develop a way of communicating between groups, John explained. Each question or proposal presented to the reference group was represented by an image. Using a grid on a board, group members were asked to indicate what they thought about the question or idea. Faces with different expressions were used to represent Good, OK or Bad. There was room on each board for comments. The next stage was to prioritise which ideas they preferred.

Each completed board from each group would be photographed and colour-coded to represent different groups. Sometimes, a summary board was used. John was at pains to stress the experimental nature of this method, tracing its development. "No two meetings were ever the same. Sometimes we asked participants to vote on issues; for example, the name of a service for a supported living scheme. Different groups preferred different methods of representation – symbols, pictures, words, photos". When they started the project, there were some initial concerns; for example, that the more articulate people would take over, but fortunately this did

not happen. At the start they made films to represent topics they were going to discuss; for example, a typical trip through a hospital, things on the ward, staff, images you would see going in, staying and leaving. Multimedia was used to set the scene, images and symbols to generate discussion, colour coding to differentiate between different groups. Then they fed back results to the groups, again using multimedia. Reports from each board would show, for example, comments boards and a summary of the key points. The events were filmed and made into a DVD.

"The result was a massive increase in participants", said John. "Attendance at the reference group more than doubled. It was really important for us to stress that everyone should be there". A significant side effect of this process was the realisation that all the other information they had produced needed to be redesigned. Making things accessible suddenly became much more of a challenge. It was no longer enough to simply write things in plain English, or even to use pictures and symbols to represent what they wanted to say. They began to use multimedia creatively, as John explained: "At our meetings, we would use subtle and simple techniques to focus attention; for example the use of music before a meeting starts, then the music stops to indicate that the meeting is about to start. We also used sounds to show movement from one item to the next on the agenda".

They have some exciting future plans. "We are looking at multimedia profiling, developing personal web pages for people, building secure areas, photo-libraries, comprising film and sound. Previously we used DVDs but found them too static. They work well for histories but are not interactive or easy to update". They plan to use the computer as an intermediary – an interpreter, fast tracking communication development. "The problem we have is making it secure, always difficult for smaller organisations. We need to develop software – such as touch-screen software – for people to use so they could update their own live webpage by touching symbols and images.

We are hoping to develop options to use this in care planning and, ideally, also for creating live graphics at meetings". John's vision would have a revolutionary impact on partnership board meetings – as well as on many people's lives – were it to become a reality. John Burley is an inspiring and enthusiastic advocate for people with learning difficulties whose organization has tackled the challenge of inclusive consultation and achieved some success. He was thrilled to hear that our supported self advocacy group in Islington are planning to develop their own inclusive consultation methods for the partnership board, saying typically, "I'm sure you'll make it much better than we have managed so far".

The promise in Valuing People of dramatic change and improvement for all people with learning difficulties has still to be kept. For many people, the quality and progress of local partnership boards reflect their frustrations with this state of affairs. I believe this is because partnership

boards do not practise real partnership or inclusive consultation. Proper thought and planning is required to avoid excluding people who have learning and communication difficulties. Any hope for a future society where all people with learning difficulties are really able to lead the lives they want depends on it.

Group consultation - a suggested process

Include:

- people closest to individuals (supported)
- local advocacy groups (discussion)
- speech & language therapists (signs and symbols)
- communication (person centered planning) workers (supported)
- intensive interaction facilitators (supported)

Ensure participation by:

- offering a choice of a range of different groups, eg. discussion, signs & symbols, supported.
- develop ways of communicating between groups
- use multimedia to set the scene, indicate endings and beginnings, signs and symbols to generate discussion.

But most importantly ...

Innovate and act on feedback!

Resources

- Valuing People Website
- Information for All, RNIB 2005. Available from RNIB Customer Services, PO Box 173, Peterborough PE2 6WS, tel. 0845 702 3153

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