

# **‘It’s my meeting’: Finding ways to involve people with high support needs in person centred planning**

**Helen Sanderson**

## **Introduction**

Person centred planning is central to the White Paper ‘Valuing People’ (Department of Health, 2001). One of the challenges this presents is how we can fully involve people with high support needs, who may not use words to speak, in person centred planning. Traditionally, when we have considered how we can involve people in planning we have concentrated on the planning meeting (Sullivan and Hooker, 2001). Person centred planning is much more than a meeting. It is a process of continually listening, and learning; focussed on what is important to the person now, and for the future; and acting upon this in alliance with their family and friends. It is vital that we think about how the person can be central throughout the process, from gathering information about their life, preparing for meetings, monitoring actions and on-going learning, to reflection and further action. There is a danger that efforts to develop person centred planning simply focus on having better meetings. Any planning without implementation leaves people feeling frustrated and cynical, which is often worse than not planning at all.

We need to thoughtfully consider how to involve people in their meetings as well as how to fully include people in making plans happen and further learning and actions. In this article I explore how we can include people in one aspect of person centred planning, having meetings. I look at what self-advocates from People First say should happen, and what this means in practice for people with high support needs.

## **Staff and manager’s views**

From talking with staff and managers about involving people with high support needs in planning their lives, people have usually talked about whether the person should be present at their meeting or not. There seems to be three main approaches to this:

- Having people who do not use words to speak in their meetings is tokenistic and therefore people do not try
- It is useful for staff for the person there, regardless of how much the person understands, as it keeps the meeting focused on the person
- It is the person’s right to attend their meeting and therefore staff need to work to make it as accessible as possible

The first view assumes that people will not be able to understand anything or contribute, and the belief that you either involve people fully or else it is completely tokenistic and therefore ‘wrong’.

The second view does not seem to address the issue of people’s understanding or contribution but instead reflects the perceived benefits for staff of the person’s presence, that the tone of the meeting changes when people themselves are there. This may indeed be the case, however the disadvantage of this approach is that the focus is

on the staff and how the person's presence may affect them rather than our responsibility to make the meeting as accessible as possible.

The third view stresses that we need to constantly be working with the person to be responsive to their communication and to be clear in ours. This should underpin all our time with the person, not just in meetings. Therefore the meeting should reflect the ongoing work of learning to listen to the person. This reflects an ongoing learning approach, where we constantly seek to learn from the person, learn to communicate more effectively, and evaluate how well we are doing.

This could be misinterpreted as everyone attending his or her meeting regardless of any other consideration. We are still hearing stories today of people being locked in the meeting room so that an administrator somewhere could tick the box that states that 'people attended their own planning meeting'. Staff often describe how attending a meeting would be an unpleasant experience for the person, because they tried it and it did not work. Rather than the 'we tried to involve her once' approach, every opportunity should be taken to improve our ability to involve people in a more meaningful way in all aspects of their life.

On many occasions individuals, who were not thought capable of sitting through a meeting, do because they feel listened to and included, and people have seriously thought about what it would take to make it a positive experience for the person.

*Steven*

*Herb Lovett (1996) describes how he used person centred planning with Steven, and how the staff were sure he could not stay in the meeting. Steven was sixteen and described by the staff as having no attention span, could not speak and that he would become disruptive in the meeting and could not possibly sit throughout it. Herb persuaded them that Steven should start the meeting with them, and that if he needed to leave he could do so, and could rejoin the meeting if he wished. As staff had predicted, at the beginning of the meeting he was noisy and restless and left the meeting with someone for a while. Later he rejoined the meeting. As part of the planning process that Herb was using, he was asking people what it would have been like to experience what Steven experienced as a child. He described how as people were talking their tones changed as people considered their own experiences of childhood and reflected on Steven's.*

*Steven stopped pacing and sat quietly and by the end of the meeting, when people were talking about how he had been systematically rejected by the service and the acceptance that he needed, Steven was curled up, calmly with his head on someone's lap*

*'It seemed to me that Steven had done two things. First, he had demonstrated to people how long he could concentrate on things when things were worth attending to. Second, he had served as a barometer for the group. When we began, people were pessimistic and unfocused. They were sure that "he couldn't ... he will never...." By the end ..as the group's optimism and sense of purpose increased, Steven steadily became calmer. Just as he had listened to the heart of people's discussion, they were beginning to learn they could listen to the hidden heart of his behaviour.'*

Here Herb demonstrates that just by the tone and focus of meetings changing, it can have a significant effect on people, and whether they want to stay or not. If all that

people have experienced are dull meetings where people have read reports about what they cannot do, where people have little or no understanding of the content of those reports, the tone of the meeting would not be one where their presence is welcomed.

How much people can understand is one of the issues that most staff are concerned about when looking at the issue of involving people. Some people think that we should always assume that the person understands what is being said to them and therefore should be included in conversations and meetings like everyone else. People sharing this view will support the person to attend the meeting and will direct conversations towards the person to include them.

Others believe that each of us experience limits to our ability to communicate and that involving people in their planning meeting requires that we understand any differences or limitations in peoples communication and respond to that.

We need to work to discover each individual's abilities, or make an informed 'best guess' at this and use this information to redesign meetings to make them as accessible as possible for people. Including people in conversations is part of this, but each individual will require different ways for us to continually learn how best to include them.

### **The views of People First**

When writing their booklet 'Our Plan for Planning', (1996) People First in Liverpool and Manchester described their experiences of planning and what they would like to change. Traditional assessments and planning meetings were usually held in an office, with several professionals, sometimes including a parent and occasionally including the individual concerned. The meeting were chaired by one of the professionals, it always takes place during the working day and lasts a set time. Minutes were taken to be typed up and distributed later. People First outline some of the changes they would like to see, and for each of these we consider what this could mean in practice for people high support needs.

#### **People First said...**

- **“people must have given time and support to prepare”**
- ***“We want to think about what we want for the future and get together ourselves before we involve other people.”***

For people with high support needs this means being enabled to record their own history, what life is like now and perhaps also what their dreams could be. One of the biggest challenges is to find ways to communicate this in an accessible way. Speech and language therapists can be invaluable in exploring ways to do this. Often, the person themselves gives us clues about how to do that, for example, Robert used to spend some time each day watching a video of his family. When the staff team who support him started to think about better ways of keeping Robert at the centre of the planning process, they thought about Robert sharing his history and what is important to him now through video. Working closely with his parents they identified significant people and places in Robert's history and went with Robert to video the places. Photographs of key people were also put onto video with narrative to explain who they were. The final part of the video gave people a good understanding of a week in Robert's life by showing him involved in his typical weekly activities. The video was shown at the beginning of Robert's meeting to help people get a better

understanding of Robert's past and life now. Robert sat mesmerised in front of the TV and applauded when it had finished. He still watches the video regularly and the team plan to update it with the new activities that Robert is now involved in as a result of his meeting.

**People First said...**

- **“people should be able to choose who attends, the venue and time of their meeting”**
- ***“Not with the managers and staff sitting behind the desk. You should choose nice room, comfy chairs”***

For people with high support needs this means thinking about where the person seems most comfortable and at what part of the day they are at their best. Some of us are morning people, who are energetic first thing in the morning but fade as the evening draws in. Others of us stay in bed until the last minute, gradually brighten as the day develops, and are at our best later in the evening. Finding out this information about the person you are planning with is important when arranging the meeting. We need to find the best time to suit the person, and a place that they will feel the most relaxed in. If the people around the person cannot find a way to help them make and communicate that decision for themselves, then they have to decide in good faith who they think the person would want to involve. A good starting-point is 'people who know and care about the person'. This may well yield a different list from 'people who provide a service to this person'.

The team who supported Jean thought about these issues when they were planning her meeting. Jean attended the local Catholic Church and sometimes attended social events in the Hall attached to the Church. She is also a food connoisseur. The team decided to see if they could have the meeting in the Church hall and have a buffet in the middle of the meeting with many of the different foods that Jean enjoys. When thinking about who to invite they drew up a relationship circle which helped them to think about who was closest to Jean. They thought about the Father at the Church she attended, two of the staff who used to support her and who are still in touch, and her Aunt, as well as some of the team members. Jean is a gregarious and friendly person, they thought that she would enjoy having this number of people around. They chose writing paper in bright colours, and wrote the invitations on Jean's behalf, and supported her to make a mark and 'sign' them. The meeting seemed very successful and afterwards the team evaluated the decisions they had made on Jean's behalf and whether next time they would try anything differently.

**People First said...**

- **“use video, pictures and photographs if you want to, instead of just talking”**
- ***“You could say what you wanted but it wouldn't happen - it was the ideas staff had themselves that they did.”***

For people with high support needs this means trying to find the most accessible ways of communicating information in the meeting.

As we have said earlier, this should be an extension of how we listen to the person and communicate with them in every situation rather than something that is peculiar to planning meetings. If the person uses objects of reference then we need to think about whether there are ways of incorporating these into the meeting, if the person uses photos and pictures then we need to think about these.

A pictorial or graphic record has vibrancy lacking in a list of words and thus has more appeal. People who may be bored during the meeting are often re-engaged through using graphics. This seemed to be the case in David's meeting. David sat through his meeting patiently but it was obvious that his attention was elsewhere. He wandered backwards and forwards. At one point he approached the graphic and his attention was engaged obviously for the first time. He looked at the images which made up other peoples dreams for him and when there was talk of his room being painted he indicated that he wanted it painted yellow by choosing one of the pens held out to him.

### **People First said...**

**“There is not point having a meeting is nothing gets done. We want results!”**  
***“plans are not worth bothering about if the same old stuff keeps coming up - it should be good ideas instead.”***

The final change the People First wanted was to make sure that something happened as a result of the plans. Developing ways of achieving real accountability to people, based on understanding them through a person centred planning process is one of the challenges of the future. Direct payments could be part of the answer, however, the key to making this empowering for the individual rather than passing responsibility from one group of people to another lies in developing a rich and real understanding of the person. Here independent facilitation could play an important role in safeguarding such a process from becoming another bureaucratic exercise.

### **Conclusion**

Involving and empowering people with high support needs in person centred planning must be seen as an extension of our commitment to learning to communicate effectively with people and responding to their communication with us. This means asking different questions and learning about people in different ways to find people's preferences and even dreams. Our approach needs to be one of continually asking what it would take to involve people more in every aspect of their life, and not just planning. Without this perspective, an investment in finding ways to involve people in a meeting where the plan itself is filed and redundant until the same time next year is futile. This will just add to our list of service abuses of people with profound and multiple disabilities. Discovering ways of empowering and involving people in developing a plan, in the meeting to agree actions and in implementing and monitoring the plan, is our challenge if the promise of person centred planning is to be realised.

### **References**

Department of Health (2001) Valuing People, London: HMSO

Lovett, H. (1996) Learning to Listen. JKP

Liverpool and Manchester People First (1996) *Our Plan for Planning*

Manchester: People First Manchester, BVEC, Ross Place, Aked Close, Longsight, Manchester, 0161 273 1221

Sanderson H, Kennedy J, Ritchie P & Goodwin G (1997) *People, Plans and Possibilities - exploring Person Centred Planning*, SHS Edinburgh

Sullivan, J and Hooker, M (2001) *Whose review is it anyway?* *Community Living*, January/February

## **Resources**

My Life – My Story. Making Personal Portfolios  
Video by Manchester People First  
Available from: Pavilion Publishing

O'Brien J, & O'Brien CL (Eds.) (1998) *A little book about Person Centred Planning*, Inclusion Press, Toronto

Social Services Inspectorate (1996) *Planning for Life - Developing community Services for people with complex multiple disabilities. No.2: Good practice in Manchester*, London: Department of Health

---