

**Why aren't person centred approaches and
planning happening for as many people and as
well as we would like?**

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The views expressed in this paper are solely those of the author.

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When I was asked to write this paper and first read the title I wasn't sure where to start, it seems like a really complicated question. Firstly I'm not exactly sure who the 'we' are and, if I am one of them, I don't know that I entirely agree with the suggestion that more and better planning is what I'd like.

So in order to tackle the question and consider some of the issues it raises I decided to think about people I know, where planning has helped to make changes and what they've been. This might help us think about what it is that matters in all of this. Why is change important and what is it that needs to change?

Nancy

Nancy is 19; she has lived in residential homes since she was 4 years old. Nancy has many labels attached to her; she is described as having a physical disability, a learning disability, and being challenging to support. The service supporting Nancy realised that she would have to move on and having learnt about person centred planning asked her if she would like to try it.

The service providers were keen to continue offering support to Nancy and so were clear that they should not facilitate the planning sessions because of their vested interest in the future.

Two experienced independent facilitators were identified who talked to Nancy about the plan. She decided to invite her parents, her grandmother, three of the six support staff, one ex support worker who she is still in contact with, the home manager and one of her friends from college.

Prior to the meeting she got a chance to think about the future and the past and as it was clear that she didn't want to talk about the past, we decided on PATH as the most appropriate planning tool.

The meeting was amazing, Nancy had thought really carefully about what she wanted. She told us about having her own house, about how she could have friends to visit, about where she would work. Everyone was really impressed by Nancy. She seemed to have thought about everything. She had realised that she would need staff to assist her and so she wanted to know how to work out

rotas. She wanted to learn how to iron, she wanted a social life which had nothing to do with disability, a boyfriend, and a job. This doesn't sound unusual for a woman of 19 but was unusual for someone with Nancy's labels. Nancy's parents were thrilled that she was so competent and had a plan although some elements of it scared them!

That should in theory be the end of that, a successful outcome all round. But nothing much seemed to happen after that, for a few weeks people helped Nancy to work on learning what she wanted and she started looking for a job but then people slowed down. No one has been looking at housing with Nancy, no one has helped her meet up with her social worker about funding. Staff have been saying that Nancy's expectations are too high and now, nine months later, people, not those at the meeting, are starting to wonder if Nancy can live alone because she is more challenging in her day to day relationships with staff. It may seem as if the planning did not help change to happen.

Did change happen? It's an interesting question because I think it did. In the room at the time of the planning people saw Nancy differently and she too saw herself differently, she believes she is worthwhile and she has a dream about having her own home and she is not going to give up on that. However the service has not changed to meet Nancy. The people in the service are not bad or being difficult they just don't know the next step and how to treat this changing and growing young woman. They don't know how to help Nancy get a social life, or to alter their service enough to offer what Nancy wants.

I asked Nancy what she thought? She's glad she planned but is frustrated with people not acting more quickly, she can't understand why some simple things like going to the pub get complicated. But at least she now thinks that she can and should go to the pub. Her grandmother has asked the staff to meet again and review progress on the plan, so something has changed for Nancy's family, they perhaps feel more empowered to intervene on her behalf. So from the outside little has changed but the small changes that have started cannot be reversed and will, over time, cause more change to happen. The issue now might be how can we help the organisation change faster so that Nancy does not have to wait for them to catch up with her.

John

John is a man in his forties, he was identified as being somebody with a severe learning disability and lately workers had been concerned about him because he was being very disruptive in the small group home (four people) where he lived.

John doesn't speak and although he has been in the same house for six years staff felt they did not know him well.

One of the staff from the house, a woman called Carol, attended a person centred planning course and learnt about Essential Lifestyle Planning. After the first part of the course she went back to work and asked John if she could work with him on finding out more about what mattered in his life. Using the questions from Essential Lifestyle planning and after talking to everyone in the house she came back to the course two weeks later really excited. She had found out one crucial piece of information which had changed everything for John. She had discovered that John needed to know that there were bananas in the house for his packed lunch the next day. If there were not he wouldn't be able to sleep. What she did was ensure that every day people checked with John that there were bananas and made up his packed lunch with him every evening. This allowed him to sleep. Prior to her finding this out the home had been applying for waking night cover to deal with the problem of John being awake at night.

Most importantly for John, Carol kept going, she kept finding out more about what mattered for John and sorting it and, as she did so, John's behaviour began to change. Violent incidents in the house reduced. Carol never said 'that's obsessional behaviour how can we change it?' she just made sure he had bananas.

Now, two years later, Carol is still working with John, he has a good Essential Lifestyle Plan and they are working together on future plans for him to move to his own home. She feels she knows him well now and really likes him. For John many things have changed, he is not that interested in bananas any more as he has many other things to think about, although he still make his lunch up the night before.

This story shows us how even a small observation or discovery can change things for people and how engaging with someone on a quest for more and better information about what matters can dramatically improve the service and quality of the persons life.

Neil

Neil is a 27 year old man who is supported in his own home by a small group of staff. He has severe physical disability, doesn't speak and moves only his right hand very slightly and his eyes.

Neil attends a day centre every day and usually slept whilst there. People supporting Neil at home described him as bright, enthusiastic, lively and up for trying anything new, people supporting him during the day described him as

tentative, unadventurous, and unlikely to understand what people suggested to him.

Together with Neil and his Mum we decided to get everyone together to plan for the future and to air these different views of who Neil is. Neil and the two planners spent a while together making sure that we understood how Neil communicated. We learnt that he would use his eyes to say no and his right hand to say yes. We decided to use PATH to plan the future. Neil invited staff he liked from both day service and his staff at home and his Mum. The day centre staff were unsure about whether or not it was worthwhile to meet, but did in the end, attend. We met together in an evening in Neil's living room, the plan took about 4 hours.

During the planning Neil worked on a dream for the future which included getting a job, making a video for television, moving to a bigger house, improving his social life, having children, getting married, the usual sorts of ambitions of someone in their late twenties. For Neil these ambitions had not been considered usual, no one even knew Neil had those ambitions. So one of the most important things that happened during the planning was that everyone treated Neil as an ordinary person and his dreams as valid. No one said this is unrealistic, Neil was confirmed as a young ambitious and adventurous man. Day centre staff realised that the reason Neil was different at the centre was probably because he was bored and had nothing meaningful to do. They realised this without having to be told.

The people who attended the plan have worked together to change things over the last year. So far they have assisted Neil to apply for a mainstream college course on a part time basis, it has been agreed that he will have a one to one worker (who previously worked at the centre). This worker will assist Neil at college and for the rest of the time do ordinary things in the community instead of going to the day centre. Neil is involved with everything that is happening and is directing the changes. The pace of change is slow but steady, Neil is getting a life.

Murray

Murray is 31 years old. He has a physical disability, doesn't speak and no one is very sure what Murray does or doesn't understand. Murray attends a day centre and we were asked to plan with Murray as the centre was trying to offer a different, more individualised service. After talking with the family, the centre staff and Murray we agreed that a MAP process would be useful so that we could learn about Murray's life before thinking about the future. Murray, his

Mum, Dad, one of his brothers, two staff from the centre and a staff member from the respite service he uses once every six weeks all attended.

As we heard the story of Murray's life everyone present realised the horror of the position the family were in. Since he was three months old his parents and brothers have lived with the idea that he will die young, this was originally that he would live for a few more months, and then a few more but his death was always imminent.. So, for the family, any thought of the future has been difficult because it will include their sons death. We all began to understand that in some senses everyone had been marking time. His mum had never worked, she wanted to spend time with her son and he had had lots of one off exciting experiences but few things had been repeated. The story lasted about an hour and was very moving but the rest of the process really fizzled out and there was no real action plan at the end. It didn't feel very successful.

A few weeks later I spoke to Mrs Brown, she said that the family had stayed up late looking at the MAP on the wall and had talked more about the past in a way they had not done before. In the morning they had all agreed to have a future. Since then they had been discussing what that would be. They wanted to meet again to think about Murray having his own home, about him having an ordinary life. Mr and Mrs Brown were thinking about moving house and she was planning to go back to college and get a job. The whole family had somehow cast off the shadow they had been living under. A big change has started for Murray but as yet the day centre has not changed its provision to Murray. Change has happened within the family but service change is still required.

So what has been the point of those stories and what are we learning about the question?

It seems as if the real focus of the question is about change, change is what we are all interested in. We need to make change happen because people with labels of disability, are often excluded from community, the contribution they have to make is often not recognised or valued. As a result many people with disabilities suffer wasted lives and early deaths and this has to stop.

Many people feel that person centred planning has a crucial role to play in making change happen. From the stories above and from other experiences of planning I believe that person centred planning, when it is honestly facilitated, will almost always create the opportunity for positive change to happen for an individual.

It can assist services to identify what they should be doing differently for people. It will build consensus for change and identify the direction that service change should take. What changes will result however are not predictable. Although it does seem that families and people who use services often begin the process of change more quickly than service providers after person centred planning. For example the change for Murray and his family is profound but may not translate into service change for some time, maybe even years, although the impetus to plan came from a desire for service change.

Why change is difficult in human services

From the stories it is clear that good planning itself is not enough to make change happen in human services. From our experience working with organisations as trainers or as consultants we think that the following list of points is useful in considering why it is difficult:

- Low expectations – people in services, those who use them and those who deliver them do not often expect better and often lack vision for a better future
- Lack of Imagination- sometimes people are unable to see that there is a problem or if they do see the problem are unable to imagine how it might be different.
- Separatist thinking- if we do see the problem we may be so used to looking for service-land solutions for our particular care group that we do not make good use of generic resources and structures
- Fixed investments-our money and staff resources may be tied up in old models, in buildings rather than with people.
- Financial inflexibility-we have few ways to move money to facilitate change
- Lack of power – Service users and families lack political and financial power
- Competition – agencies which need to collaborate to achieve change may not know how to do that
- The demand for simplicity and predictability – individualised services are more complex to design and manage, so there is pressure to move to a fixed menu of fixed models.
- Distraction – change requires sustained effort and people and organisations often move on to deal with priorities and crisis
- Anxiety – we do not know how to do the new thing and we are frightened of making mistakes or of having to learn new skills.
- Change increases costs and risks – people throughout an organisation have to be able to see the benefits as important enough to make the investment worthwhile.
- Communication – people in organisations often communicate poorly with one another, there may be agreement that change should happen but a lack of communication around how the change will be achieved.

Usually a number of those factors are in operation when an organisation faces a change problem.

We also know that before organisations embark on person centred planning senior managers have to consider the likely implications of planning for their service. We know that when planning starts with people change will be required. This is likely to centre round accommodation, jobs and relationships. It is foolish of organisations to offer planning to people without considering the implications in advance. Some organisations have enthusiastically embraced person centred planning, trained all their staff in understanding and contributing to the processes, trained facilitators and set time aside for people to have planning offered. They have then caused enormous frustration for staff and service users when they have not been prepared for people wanting to move out of group homes.

People in services also need to think about the implications of introducing person centred planning in a systematic way for everyone and whether it can be done without compromising the basic principles of planning

We have found that person centred work, because it is rooted in the values of inclusion, will always require participants to work outside of service-land and in the real world. This means that providers must think really carefully about keeping people safe whilst enabling the risk taking which is a part of all our lives.

Making planning happen

While it is important to acknowledge that more and better person centred planning on its own will not achieve real service change and that it is not a short cut, it can help with some of the difficulties listed above if it is done well. In our experience it has not been difficult to get person centred planning to happen, especially as it gets more popular and more talked about. What is difficult is to ensure that the training in understanding and implementing person centred planning is done in such a way that is most likely to influence service change.

Some things that we know about training that improves the likelihood of planning leading to change at a service level

- The most effective style of training in person centred planning is experiential
- People have to understand the historical context of services before being able to understand why change is necessary
- Groups involving staff, people who use services, and family members in co training are most effective in building a joint capacity for change in the future

- ❑ Training which includes a commitment from all levels of staff is more effective than working with front line staff only.
- ❑ It is more important to help participants understand the value base than to know the planning tools really well.
- ❑ People need to be encouraged to consider their roles, responsibilities and personal commitment to change
- ❑ The implications of moving from 'power over' to 'power with' which is required by working in a person centred way need to be considered.
- ❑ It has to help people think creatively without additional resources and outside of service-land.
- ❑ It has to ensure that people providing services find out the gifts and contributions of the people who use services

When we work with organisations that want training in person centred working we ask them to think, from the beginning about change and its implementation.

When we offer this training we have to be mindful of the real people who receive it, staff who are generally good people, who may feel unsupported, who may not understand why things need to be different. The list above (why change is difficult) applies to individual staff as much as organisations. People working in services must be managed in a person centred way if they are to understand properly how to treat people using the service in the same person centred way.

When we include carers and service users in joint training with front line staff and managers this all becomes even more meaningful, people can see each other as real people and prejudice on all sides can be addressed. This style of training then builds capacity in the user and carer movements which may be a more effective way to make change happen.

Finally

Perhaps we need now to be asking ourselves 'What are the next set of questions to ask?' Some of them might be:

- ❑ When we say we think there should be person centred services available what do we mean?
- ❑ What do person centred services look like and how are they different?
- ❑ How will we recognise and evaluate them?
- ❑ How do we get people included in the real world more?

- What do I need to do to make a difference?

If we don't ask those questions we will be in danger of creating more of the same and only calling it something different. We need a vision for the future and we need it now because people who have been excluded from society should not have to wait any longer while we catch up.

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