

**Hands off my plan!
Making sure that people with learning
disabilities stay in control of
person centred planning**

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Introduction

This guide is for

- Partnership Boards,
- local groups and
- local people

It is to see if they are making sure that people with learning disabilities stay in control of person centred planning. We want you to think what is it like for people with learning disabilities who are making person centred plans



What do we mean by self advocates leading planning?

Valuing People came with some guidance about person centred planning. It said people with learning disabilities should have the chance to lead their own plans.

What this really means can be confusing.

Person centred means putting the person at the centre - thinking about their life from their point of view. We think that if you are at the centre of planning, you are leading it.

Leading (being in control) is different from trying to do everything yourself (being independent).

We all have family, friends and people we pay, to help us in our life.

Person centred planning is thinking about how to connect with people to have a good life. Being with the people you want to be with and living life the way you want to.





Lots of the tools of person centred planning need a ‘facilitator’ to help them work properly.

This person will help you think about what you want for your life.

They will help you have the right conversations with the right people.

Because of this, we think that it is not usually a good idea to try to facilitate your own plan.

Imagine trying to cut your own hair – it wouldn’t work very well as you need to be able to see all the way round!



We do know that people with learning disabilities want to be facilitators.

Being a facilitator can be exciting but it can also be really hard.



We are going to work with people with learning disabilities over the next few months to find the best ways that people can become facilitators.

The most important thing we are saying is that people with learning disabilities leading planning means more than just people learning to be facilitators.

There are five things we think need to happen so that people with learning disabilities can lead person centred planning:



1. People with learning disabilities have the chance to find out about person centred planning.



2. People with learning disabilities have the chance to lead their own plan



3. People with learning disabilities have the chance to help other self advocates who want to plan



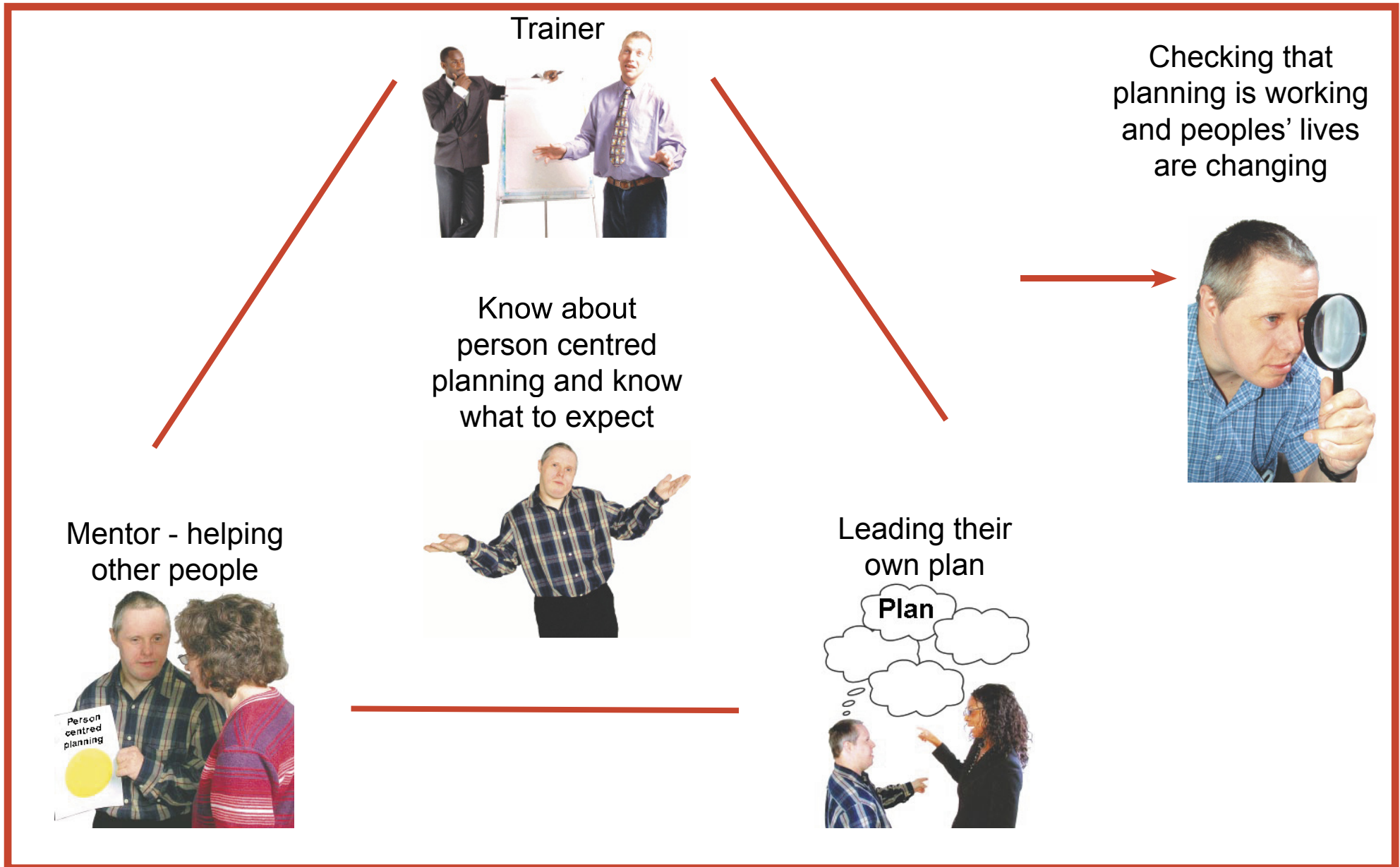
4. People with learning disabilities have the chance to lead training about person centred planning



5. People with learning disabilities are part of making sure that planning is working and people's lives are changing

The picture on the next page is to help think about this.

People with learning disabilities leading planning



How to use this pack

The pack looks at each of the five things (shown in the picture on the last page). There are different ways to use the pack. It does this by telling the story of 'Lizzie'.



You could use it yourself if you have planned or are thinking about planning. You could see if your experience is as good as Lizzie's.

You could use it with your local self advocacy group. You could check if your local council are doing everything they can to help people plan for their lives.



You could use it in your local partnership board or implementation group (the group whose job it is to make person centred planning happen) to see if they are doing all they can.

You can use it to celebrate the things you are getting right.

However you choose to use it, it is always a good idea to tell people how well you think that things are going for you or for people where you live:

- Let your Partnership Board know
- Write something for your local newsletter
- Tell people who use and provide services
- Make and share an action plan on how you will make things better





This is Lizzie – her story is made up.

She is looking out for people with learning disabilities to make sure that they get to stay in control of planning.

She will talk about what person centred planning was like for her.

You will have the chance to think about how your experience of person centred planning compares to Lizzie's – is it:



As good as Lizzie's experience?



Not as good as Lizzie's experience?



Much worse than Lizzie's experience?



1. Self advocates have the chance to find out about person centred planning.

If you do not know about person centred planning then you can't decide if it is useful to you or not.

This is what Lizzie says:

'My support worker told me about person centred planning first.

She gave me a small book about person centred planning that people from my local Partnership Board had made.

It was easy to understand and had stories of other people with learning disabilities who have made their own person centred plans.




I went on a one-day training course that explained about person centred planning and what it means. Kath, who I know

from my self advocacy group, was one of the trainers. That made me feel much less nervous. She talked about how she had planned for changes in her life and it made me think that I could do the same.

After that first course, I got talking to Kath and she told me all about her plan and the different ways of planning.. I learned how planning can help people make change their lives. I decided that I would like to make a plan for changes in my life.



Think about your experiences compared with Lizzie's. Add up the numbers in each column. There is space to write any comments you have about your own or your group's experiences.

	 As good as Lizzie's experience?	 Not as good as Lizzie's experience?	 Much worse than Lizzie's experience?
I have had the chance to find out about person centred planning			
There was information about person centred planning for me (a video, tape or booklet etc)			
I could get information about how other people have made changes in their lives through person centred planning - their stories			
There were people I could talk to who had already made their own plans.			
There were people with learning disabilities leading the training I went to			
I had the chance to find out more about person centred planning if I wanted to			
I could find out about other things that help with person centred planning. Things like Direct Payments and Supported Living			
Total numbers:			

Other things that are important:



Good things to do to make sure that people with learning disabilities have the chance to find out about person centred planning

The Learning Disability Partnership Board should be making sure there is time and money so that people with learning disabilities can find out about person centred planning. This could mean:

- Giving money to local speaking up groups to develop information and training that is just for people with learning disabilities
- Getting people with learning disabilities from other places to come and talk about what they have done.

Make sure that there are regular training sessions where people with learning disabilities can find out about person centred planning and what it means:

- What person centred planning is and how it works
- What it could mean in their lives
- What help they can expect in helping them to make a plan
- What they need to do next if they want to plan

Plan some training sessions that are for anyone who wants to know about planning and some sessions just for people with learning disabilities. Make sure people with learning disabilities are part of the team who leads training sessions

Make sure that there is the chance for people to find out about person centred planning without having to go to a session. It is a good idea for there to be people who can tell people with learning disabilities about planning, on their own or in a small group. This is a good job for members of a speaking up group.

Valuing People says that there are some groups of people who are a priority for person centred planning. It is very important that people in these groups have the chance to find out what person centred planning means:

- Young people in transition
- people living with older family carers
- people moving out of long-stay hospitals
- people who use big day centres
- people living in NHS campus accommodation

This means that you are going to have to work with different places and organisations – schools, day services, hospitals etc. You will need to find out the best way in your local area to make sure this happens.

Make sure that there is good local information about person centred planning for people with learning disabilities. Information needs to be written in Plain English and it is a good idea to think about other ways sharing information (video, tapes, etc). People with learning disabilities could make up a play about person centred planning and show it to people in different services

Stories of the plans that people with learning disabilities have made are really important. You need to make sure that you collect and share them. This could be a book, a video or a CD. People should have the chance to tell their stories – the Partnership Board is a good place to do this

Not everyone will want to make a plan right now but there needs to be a chance for people to spend time thinking about their lives and their dreams. One self advocacy group organised a day for people who do not use words to speak. Everyone came to the day with someone they like and brought something special to them. There were chances for people to try new things, including foods, reflexology and clothes. One person found that he really liked having his feet massaged. This was something that no one knew before. It helped his supporter plan new things to do with him.

Some people with learning disabilities will want to find out more about person centred planning. There should be the chance for people to go on a longer course or to spend more time talking to people who understand planning.



2. People with learning disabilities have the chance to lead their own plans

After people have found out about person centred planning and understand how it could help them to make changes in their life, they may decide that they want to lead their own plan.

This is what Lizzie says:

I decided that I wanted to plan for myself. I wanted to be in control of it. I wanted people to help me with my plan – to facilitate it.

I asked my key worker and she said that there were people from social services who were facilitators.

I wanted to plan with someone independent.

My key worker asked the person centred planning coordinator who else could help me to plan and she introduced me to Tom.

Tom works for an organisation that supports people in



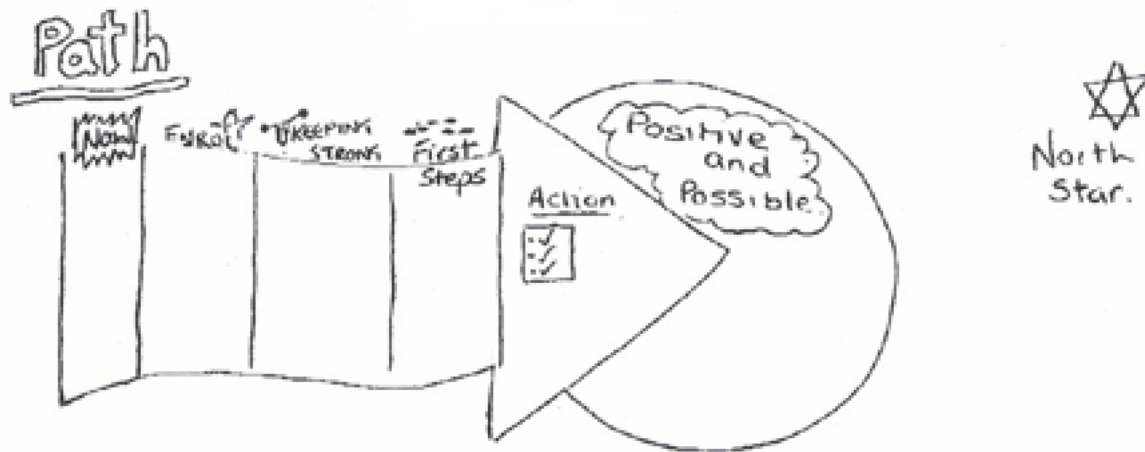
their own homes.

Tom and his friend Julie came to talk to me about my plan and we got on well so I decided to ask them to help me plan. We thought about who the important people in my life are and made a list.

Tom helped me to decide who I wanted to invite to help me plan. I decided to have my first planning meeting on a Saturday evening.

I wanted a Newcastle United theme, as I'm a big fan. I invited the people to the meeting and asked everyone to wear only black and white. Food and drinks were black and white and I decorated the room.

I wanted people at my meeting to help me to dream about my life and things I want to change. I really wanted to think about how I could get my own house.



Tom helped me decide to do a PATH.

We drew the PATH on a big piece of paper on the wall and at the end of the meeting Tom took a photo of it.

I decided that everyone who came to the meeting could have a copy.




I also have the big paper on the wall in my bedroom – it reminds me what my dream is.




Everyone who came to help me plan agreed to help with one thing to make it happen.



Think about your experiences compared with Lizzie's.

Add up the numbers in each column. There is space to write any comments you have about your own or your group's experiences.

	 As good as Lizzie's experience?	 Not as good as Lizzie's experience?	 Much worse than Lizzie's experience?
I decided that I wanted a person centred plan, because I wanted to make some changes in my life			
I was able to choose the people I wanted to facilitate my plan			
I was able to choose independent facilitators (someone not working for the Local Authority or Health Trust)			
I chose who was involved in my plan and who came to meetings			
I chose where the planning happened			
I chose when, how often and at what time the planning happened			
I was able to make the meeting really special – how I wanted it. Everyone knew that it was my meeting			

	 As good as Lizzie's experience?	 Not as good as Lizzie's experience?	 Much worse than Lizzie's experience?
I worked with the facilitators to think about which way I wanted to plan. There are different ways with different names, like Essential Lifestyle Planning, PATHs etc They helped me to understand this.			
I got help to collect information about my life for my plan			
I decided how I wanted information to be recorded and who sees it (or is told about it)			
I have my own person centred plan. I decided who has a copy. No one can have a copy without me agreeing			
I worked with the people who helped me plan to decide who did what to make the plan happen			
I talked with the facilitators after the plan about how well it worked for me and how I would do things differently another time			
I had the chance to write my story about planning to share with other people			
Total numbers:			
Other things that are important:			



Good things to do to make sure that people with learning disabilities have the chance to lead their own plan

Where planning meetings are held is really important. Some people do not know many places – maybe they only go to a day centre so they might need some ideas or help to think.

Planning change is special and deserves a special place. Joe decided to hold his planning meeting at his day centre, he invited his friends and family. On the day of the planning meeting, once everyone had arrived, Joe explained that he did not feel like the day centre was 'special enough' to celebrate his life.

Joe promptly took everyone out to a restaurant to have a meal whilst planning.

Sometimes people may not have the words to say how they want their meeting to be. People may be worried that someone may not stay involved or present during their planning.

Peter is 18 years old. The person facilitating his plan helped people think about what Peter really liked to do - 'Trampolining' was the answer. Peter loved trampolining, so planning took place both around and on Peter's trampoline.

Thinking of ways of helping people to collect their own information for their plan is important. Terry decided to make a video about his life. It was hard to do this as Terry had lived in hospital for a long time and did not know if he had any family.

Terry's support worker in the hospital worked hard to find out. He found old hospital records and talked to staff who had worked at the hospital when Terry was a boy.

They found where he was born and Terry went for a day to visit places he remembered.

To lead your own plan, you really need to decide who is there.

Sarah spent a long time deciding who she wanted to help her plan. She chose 4 of her best friends, her Mum, her sister, her favourite support worker from the day centre and her Priest. She knew that she did not want to go to the day centre any more and she wanted people to think with her about how to make that happen.

She had a Care Manager but she had only met her once and she did not want her to be part of the planning. Sarah decided to ask her Care Manager to meet her after the plan was made.

This way they could talk about what needed to change in the services that Sarah gets.

Bob used his plan to move from a big residential home to his own place. So many changes happened in his life that he really wanted to tell other people.

Bob has become a regular in his local pub on a Sunday and recently was part of the team that won the pub darts championships.

His team told their story to the local paper and took the chance to remind everyone how important it is for everyone to live the life they want.



3. People with learning disabilities have the chance to help other people who want to plan

After someone has finished their first person centred plan and things are happening in their life they may want to help other people plan.

There are different ways to do this. This is what Lizzie says:



‘My plan helped me so much that I wanted to be able to help other people.

I talked to the person centred planning coordinator and she needed people who had already made plans for themselves to work with people who are trying to plan. This job is called being a mentor.




I go to people’s planning meetings with them and work with the facilitators to help make sure that the meeting stays on track with what the person wants.

I have also met people who want to move house, so I tell them about all things I had to do and give them tips on local decorators etc.

I talk to them about my experience and help them think about what they want.

Think about your experiences compared with Lizzie's.

Add up the numbers in each column. There is space to write any comments you have about your own or your group's experiences.

	 As good as Lizzie's experience?	 Not as good as Lizzie's experience?	 Much worse than Lizzie's experience?
When I had finished my first plan I had the chance to tell other people with learning disabilities about person centred planning.			
I was able to help other people who were thinking about similar things to me (for instance, where to live or getting a job – whatever I decided to change in my life). I gave people information and advice.			
I had the chance to work as a mentor. I go to planning meeting with people to help make sure the planning stays on track with what the person wants			
Total numbers			
Other things that are important:			



Good things to do to make sure that people with learning disabilities have the chance to lead their own plan

One important job on the Partnership Board is to be the Champion for person centred planning. Arabella is a woman with learning disabilities. She is a Champion for Person Centred Planning and a member of the Partnership Board. She is working with the local leisure centre to help them think about being more welcoming to people with learning disabilities. Two of her friends, Sam and Kerry, made plans for themselves that included losing weight. They wanted to go to their local keep fit class at the leisure centre but were nervous about trying it for the first time. Arabella talked to the staff at the keep fit class and they agreed to welcome Sam and Kerry and help them out for the first few sessions.

There needs to be the chance for people with learning disabilities to train as a facilitator if they want to. We know that this is difficult thing for people to learn to do. John has finished a course to help him learn how to be a facilitator. He has shared what he has learned with people at his local self advocacy group. John has been a mentor for 2 other people who are planning for themselves. He is not sure yet if he wants to try and facilitate a plan for someone. He is looking forward to working this out with other people with learning disabilities and facilitators where he lives.

Being a mentor is a really good way of people with learning disabilities helping other people to plan for themselves. This means someone with learning disabilities helping someone else as they make their plan. They can give practical help and support. They can also make sure that the person really does get to say what they want in their planning meetings. Speaking up groups could work with facilitators to design training for this role.



4. People with learning disabilities have the chance to lead training about person centred planning

It is important that some people with learning disabilities that know about and have been part of person centred planning have the chance to work as trainers.

This is what Lizzie said:

One thing I was really interested in doing was learning to be a trainer so I could tell other people with learning disabilities about person centred planning.

I remember how good it made me feel that Kath was on the first training day I went to. I am part of our local training team.

Along with Kath, and 2 facilitators, Sue and Jo, we do awareness training.




I talk about my gifts (the things that are special to me that I am good at) and ask everyone on the course to write down their gifts and put them in the gift box.



It is good fun asking people to think about the good things in life, like my boyfriend, my Mum and sister and my own house.

Think about your experiences compared with Lizzie's.

Add up the numbers in each column. There is space to write any comments you have about your own or your group's experiences.

	 As good as Lizzie's experience?	 Not as good as Lizzie's experience?	 Much worse than Lizzie's experience?
People with learning disabilities have the chance to join the training team that tells professionals, families and other people with learning disabilities about person centred planning			
The training team works closely with the local speaking up group to plan training about person centred planning			
People with learning disabilities are able to learn more about being a good trainer			
There are people with learning disabilities who train professionals about rights and values			
Total numbers:			
Other things that are important:			



Good things to do to make sure that people with learning disabilities have the chance to lead their own plan

It is a good idea to have a local training team to organise and do all the training.

In one place there is a local training team made up of a self advocate, family member, advocacy worker and staff from Social Services. The team deliver awareness training to anyone who is interested in Person Centred approaches and planning. Twice a year they have an away day where they think about how training is going and plan new sessions. They also think about training they need as a team or on their own.

It is really important that new support staff go through induction training that is about respecting and supporting people's rights and choices. People with learning disabilities and/or families must do this.

One Partnership Board makes sure that the local self advocacy training organisation has the contract to do this. They sometimes work in partnership with the carers' association to do this.

People with learning disabilities have an important role to play in promoting Valuing People and person centred approaches.

One drama group worked on a play about how people's lives could be different if Valuing People really happens in their area. They did a road-show which included a performance for their local councillors.

5. People with learning disabilities are part of making sure that planning is working and people's lives are changing



Person centred planning should change people's lives. If this is not happening then there is not much point in people having plans.

This is what Lizzie said:






When I had been involved in person centred planning for a while I wanted to make sure that people's lives were really changing – like mine did.

I asked to join our Implementation Group, the 'making person centred planning happen' group. This is the group that the Partnership Board set up to make sure that all the right things happen to do with person centred planning.

They agreed that it was important to find out if people's lives are actually changing when they have planned. I go out and ask people who want to speak to me, what they thought of their planning. It is good that I do this because I know what it is like to plan, so I ask the right questions for people and their families.

I tell the Partnership Board how person centred planning is working for people. I went to see one woman who had planned. I found out that she did not choose the people who she wanted to be involved in her planning meetings, the staff did. I told her this was wrong and I have put it in my report to the Partnership Board.

Think about your experiences compared with Lizzie's. Add up the numbers in each column. There is space to write any comments you have about your own or your group's experiences.

	 As good as Lizzie's experience?	 Not as good as Lizzie's experience?	 Much worse than Lizzie's experience?
People with learning disabilities have the chance to be members of the person centred planning Implementation group			
The Learning Disability Partnership Board has a clear vision for how person centred planning should work locally and how people's lives and services should change. People with learning disabilities are part of checking that this is happening			
The Learning Disability Partnership Board regularly hears stories from people with learning disabilities about how person centred planning is changing people's lives.			
The Learning Disability Partnership Board hears when planning is not working and when people with learning disabilities are not getting the chance to plan			
Total numbers:			

Other things that are important:



Good things to do to make sure that people with learning disabilities have the chance to lead their own plan

One Partnership Board has set up a group of people with learning disabilities and parent/carers who go out and meet with people who have planned. They ask them questions about what this was like. The group ask questions about the facilitators, if the person was in control of planning and most importantly, what has happened since planning. Every six months the group tell the person centred planning Implementation group what things people have said. They also say what worked for people and what did not.

It is important to get the right people to train to be facilitators. One way of doing this could be for people with learning disabilities to be involved. The person centred planning co-ordinator could work with people with learning disabilities to think about what makes a good facilitator. They could also be involved in choosing who gets a place on the facilitator training course.

The person centred planning coordinator needs to know how people's lives and services are changing. It is important that the coordinator spends regular time with people in the services that they use. This means that people have the chance to tell their stories, good and not so good.

Have a conference to celebrate the good things that have happened for people through planning. People can tell their stories about their circles of support and how they work.

Lizzie and her PATH



Lizzie says:

'Planning change is not easy but anything can happen if you put you mind to it!

Good luck'

Photos taken by Kate Fulton, and from the Worth 1000 Words photobank
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