

Families Leading Planning in Coventry and Warwickshire



Why now? Valuing People

People who have learning disabilities have called for the realisation of their rights, inclusion, choices and independence in the new legislation Valuing People: A New Strategy for Learning Disability for the 21st Century (Department of Health 2001). Person Centred Planning is a central theme of this legislation to enable these things to happen.

The Department of Health describes Person Centred Planning as " a **process of continual listening and learning focusing on what is important for someone now and for the future: and acting on this in alliance with their family and friends**". It naturally places people who have learning disabilities in the context of their family and community. Valuing People recognises that families want their opinions and expertise about their relatives to be an integral part of decision-making about the people they love.

Additionally there is finally a growing acceptance by people like professionals, service providers, teachers, and care managers that families make key contributions and have many skills and immense wealth of experience which they have learned from bringing up the people that they love.

Valuing People has called for Partnership Boards to provide support to families who wish to lead Person Centred Planning. It states that " *...in most localities, support for people, families and circles to undertake their own planning is very limited. Partnership Boards should invest in such developments as part of their Person Centred planning frameworks.*"

A key outcome that Partnership Boards should be looking for " *...are increasing numbers of families that can share positive stories about how they were trained and supported to plan and that services welcomed their*

planning and were flexible and responsive, and that their lives have changed in a positive way."

Why now? Coventry and Warwickshire

Context

During 2003, Helen Sanderson Associates was commissioned by Valuing People to run a series of awareness days for the region for families about person centred planning. The hope was that from these sessions that a group of families in the region would wish to pursue training in more depth to lead plans for the people they love. After running 2 of these events, it became apparent that this approach was not going to be successful. It was agreed that there was a need to work in local areas so that families could see connections with each other and local support and effect change in this manner. In April 04, lead officers, PCP Coordinators from Coventry and Warwickshire and Cally Ward met with Alison Short - Helen Sanderson Associates to agree a way forward with this work.

The agreed aims were

- Families having the opportunity to plan
- Partnerships boards learning from these people's experiences.
- Partnership boards looking at what needs to happen to make these plans real - strong focus on action and removing barriers
- Sharing learning together across 2 areas

Both areas had had person centred planning awareness events and therefore had a group of families already to move forward with planning. It was felt that due to this that there was no need to run more awareness days.

Resources for the programme

There were 10 days of training time agreed for the programme as a whole. 2 had been delivered during 2003. Therefore there were 8 days to use for the programme during 2004.

We agreed to use the resources in this manner.

1 design day - Before the course began we would bring together some families and service workers to answer the following questions

- Where are the local family groups and organisations are and think about families who may be interested?
- How can we invite families to join the course by considering where to use personal invitation, where informal introductory sessions may be helpful, where fliers and invitations could be used?
- How to ensure that families are fully supported on the course, who can do what and agreeing responsibilities for this?

5 days for the families to develop the plans with and for the people that they love.

2 days to look at how we can enable families to implement their plans.

One of these days was used to help service workers to support families to implement the plans they have developed. In the context of this programme we called these workers implementation allies. The final day was used to look at what next for Coventry and Warwickshire in the light of the families and allies experiences and new Partnership Board Guidance regarding supporting families to plan.

We agreed that we would support 16 families on the course in total.

13 families were recruited to the course. We supported 9 people to complete the taught course. We had 2 families that decided that this approach was not their right for their family currently and did not wish to continue and 2 other families that wished to be supported by local PCP facilitator. This has been provided.

Who was it for and who participated?

The course was for any family member who wanted to support their relative to plan.

Families from across Coventry and Warwickshire took part in this learning.

The group consisted of all mothers and one sister. We had one family member who is Asian and she had an interpreter. This group of family members all had adult family relatives. Additionally the people that the families were planning with and for had a wide degree of specific needs relating to their disability. The range of support that people were using included living at home with their relatives; some were at college or used local day services and some one lived away from home.

Everybody that came to the course had self-selected to join either through information that was sent out about the course by the PCP coordinator or through the awareness days.

Here are some of the reasons that family members joined the course. They said they wanted to

- *To enable my daughter to make her own choices*
- *To help plan for the future*
- *To help and find out how to get quality services to get a good quality life*
- *To learn how to plan with my daughter, for her adult life*
- *To look again at my daughter's capabilities and make plans to make them as independent as possible*

What was the course made up of?

- We started with a 'design day' in May 04 with the PCP's Coordinators, Partnership Board Worker for Coventry and Warwickshire and some families and service workers to adapt the course for Coventry and Warwickshire.

We agreed that the following factors would make the course go well by asking

If we are going to be really successful what would we

See

Happy families
Inclusion
Good attendance
A future
Fuller lives
Things being done differently
Good support
Services responding to plans
More buildings and taxis accessible
Happiness - less stress, tension, battling
Everyone will have information in a way that we understand

Hear

We hear more from the person
Families telling their side
Positive stories
At long last
Listened to
Hope for the future
Opportunities / choices
Happiness and laughter
Families being valued
Families' telling services what to do
Ability not disability
What next - this is the beginning?
Families telling other families about PCP
That more families are asking for PCP

Feel

Comfortable
Empowered
Valued
Positive about the future
Whole
Listened to
That families have made a difference
Accepted

Not alone
Not having to fight
Families feel, good
The person feels good

Do

The person's plan is happening
Outcomes into action
Changes in services
More families being involved
Lives changing for the better
Real change
Information will be translated and accessible; celebrate happiness
Better quality of life for the whole families
Raising awareness of people rights
Raising the rights of people who have learning disabilities

The sessions for families

The sessions were structured to allow families to work through a manual called Families Leading Planning. Each family has the manual as a resource from the course and they will be able to use this to continue to update the plan as they learn more about the person in the future.

There were 5 sessions provided to families, which started in June and finished in November 04. The Person Centred Planning Coordinator Jackie Grove from Warwickshire and Clare Wightman from Grapevine, Coventry provided individual support to families in between the sessions. Additionally other local Coventry and Warwickshire workers helped during the course on the sessions where family members were developing and writing the plans. This was intentional to build local relationships for the families so that when the training had finished Local support was present.

Each day began at 10.00 and finished at 2pm. Participants were offered to stay on later for individual support by the trainers.

The training always included lots of experiences and examples from families who had used Person Centred Planning. As family members got going with the plan, there were opportunities on each session to look at

what was going well, and celebrating that with each other, and to work on anything that was not working well.

Implementation Allies

There was a strong desire from Coventry and Warwickshire to look at how service workers could help to support families with this initiative. Up until this point the course had always been solely for family members with little integration with service workers. On this course we used one day to help service workers to learn how to support families. We have called these people Implementation Allies. These allies came to the sessions where the families were developing the plan and also to the action planning and on-going learning session. It felt important that these sessions were shared.

Allies - What are they?

It is becoming clear that families are very able to develop plans for and with the people who have disabilities that they love. However families are saying that to enable these plans to become a reality that there is a need to have support.

This support can come in many ways but it has been noted that it is useful to have support from someone who "knows how it is done around here".

What will an ally do?

In a nutshell they will support a family to implement the person centred plans that they have drawn up.

Stone (1999) has said "an ally means getting along side people and working along with them to make sure that any changes have the best possible impact on the person... An ally understands how the system works and tries to use what is good in the system."

An ally will

- Act with the person who has a disability and their family on the actions set out in the Person Centred plan.
- Will respect that the person who has a disability and their network are the decision makers

- Be free to cross whatever system and organisational boundaries as necessary to help the families make the plan happen.
- Provide and help families to find accurate information
- Use your local contacts and networks
- Utilise the family's resources and networks.

Here is Coventry and Warwickshire said about the role of the ally

Providing Information

- Use local knowledge
- Use knowledge of services
- Signposts to information, help and contacts
- Supporting the development of user friendly information

Style of support

- Encouragement
- Honesty

Unblocking Barriers

- Think Big
- Help to problem solve
- Help families to prioritise

Action

- Commitment to action

Listening

- Listening to family and person
- Be there to talk things over
- Offering listening support
- Just listen

Influencing services

- Helping families to put together agendas for action and forward planning
- Link to services
- Awareness raising

We asked family members who they thought could help them and be their allies but found that this approach was fraught with logistical problems when it came to releasing staff. So the PCP coordinators - identified 6 people from each county to take this role. These workers came on a one-day course to examine their role and to look at how practically they would support these families. Families were also able to say if they did not wish to be supported by any of these allies. This did not happen. This is what the workers said about the day

- *Great to have time to really listen to personal experiences*
- *Really feel that it is possible to support families*
- *Good to have chance to define how we are going to do this locally*
- *Great to have time to think through ideas and roles*
- *Really enthusiastic about supporting families*
- *I'm going to look at it another way round and see families as allies.*

Who led the course?

The course was led by Barbara Coles Families Leading Planning UK and Alison Short Helen Sanderson Associates. In addition Irene Yates provided support during the session. She is a family member learning how to support families with planning. She is part of Families Leading Planning UK.

What were we expecting to achieve in Coventry and Warwickshire

- Families would produce a plan with and for the person they love.
- Families would learn how the plan could help make positive life changes for their family member
- Families would find out how to continue to learn about what is important to the person and be able to take on going steps to ensure that they have a positive future.
- Coventry and Warwickshire would have some families that had led planning and would be willing to share their experiences with other family members who want to learn.

- Coventry and Warwickshire through this experience would be clear about the next steps to take in supporting families to lead plans.

What has happened – what have we achieved?

1. Families would produce a plan with and for the person they love

All the family members have started a plan with and for the person that they love. 5 family members were able to produce a plan by the end of the taught sessions. Others need more on going support to enable these plans to be developed. This is being provided locally.

2. Families would learn how the plan could help make positive life changes for their family member and families would find out how to continue to learn about what is important to the person and be able to take on going steps to ensure that they have a positive future.

During the course with the family's permission we recorded what they said and took photos as the group progressed with their learning. This approach to learning enabled us to demonstrate the above outcomes and to produce rich quotes directly from families that can be used to share with other families who are interested in Person Centred Planning in Coventry and Warwickshire in the future. What participants have said has been grouped under specific headings.

Getting the system to respond

Pleased that a manager said day care workers should fill in the forms and he would bring this issue to the centre staff attention

Getting feedback from the day centre staff

To see so many service workers here to support.

That services will support families.

Better communication between home & services - not just contacted with negatives.

Spreading the word

My daughters 'head teacher' has asked me to talk at a staff meeting

Personal achievement

The smile on my daughters' face when she heard what people has said about her

Creativity

Older couple going to have a gathering when it is the dad's birthday - they got inspired by the video clip and they are going to use the garage as they are converting it to a gym and can use all the wall space for posters before it is decorated.

Involving people

Church being willing for us to put information up so people can put down their thoughts of our daughter.

People have interesting perceptions of our daughter.

Amount of information that some people have been able to give

I learned more about my son from other people's comments.

Friends and family have been very interested in what the plan is about and have been very positive in their response.

Supporting the person

It makes 'people' face and respond to the person at the centre of PCP.

New learning and sharing

Being able to be offered a vehicle to focus on the specific needs - assists in easing the stress.

Being able to share with others and learn from their experiences/successes.

Action

It has brought issues and concerns out into the open.

3. Coventry and Warwickshire would have some families that had led planning and who would be willing to share their experiences with other family members who want to learn.

Coventry and Warwickshire now has a group of families that have experiences that they can share and some of these families have been asking how they can support others and what is going to happen for other families. They wish for people to have the same opportunities.

4. Coventry and Warwickshire have a group of service workers that now have experience in supporting families to develop and start to implement plans that they have been developed by the family.

5. Coventry and Warwickshire through this experience would be clear about the next steps to take in supporting families to lead plans.

On the last day the participants from this course, senior managers, development managers and the allies identified what they wished to happen next. This was set in the light of new guidance to Partnership Boards regarding supporting families to lead person centred planning. It was clear that families wanted more support for themselves to continue their learning and a commitment that other families would have the same opportunities to learn as they had.

What Participants thought of the experience?

Here is what people said at the end of the course.

Families

Thank you for all the information to get me started on doing my daughters plan - I will try and set up meeting with people who work with my daughter to start taking the plan forward

I feel positive about having a meeting and the planning for the future. I feel that I am at the middle on that tree.

I will meet with ally when plan comes back

Carry on having monthly meeting to implement the plans

Finish putting the plan together and get it checked

My time spent exploring this exercise has been well spent and efforts rewarding

Very nice

Allies

Lets get started and get implementing

Positive day - good to think about this form different angle

Have really enjoyed working with families - thank you for sharing

Looking forward to problem solving and offering different ways to help with the plan

Thank you to all the parents for sharing - is would liked to have been more involved with a family but would liked to continue

Enjoyed learning about different ways / approaches to PCP

Find out what support other families who are not where want from me

Positive networking with Coventry - there is more than one-way

Very helpful

What are the concerns for Coventry and Warwickshire?

There appears to be a recurrent theme regarding how services will support and respond to families. Families have welcomed this opportunity to learn and have been very encouraged by the support that they have received from service workers as allies. But they need for this to continue.

There is a need to continue to enable service workers to learn how to respond to families regardless of whether this is around PCP or not. There is a general need and a specific need around how to enable service workers to be able to support families to take the lead in planning.

Families are concerned that sustained effort will not be there in terms of on going support and opportunities for other people.

There also appears to be a real need for families to hear about what's possible - this has been helped by the 2 counties working together.

Support for family members from different ethnic backgrounds. There needs to be more focused effort around supporting families and working with their interpreters to enable this to happen successfully. We have been exploring this.

People were concerned that there is a need to keep supporting this original cohort of families so that people can learn from their experiences and report this back to the Partnership Boards in terms of implications for change. Protect and support the families and their allies!

People also wanted a community of practise approach - regular meetings where they can be supported to continue to implement the plans

Families have welcomed the opportunity to learn in detail with the support of allies about Essential Lifestyle Planning however they feel that there is a wider need for families around understanding what is possible and the system and on going support. People are very interested in extending their networks and looking at family leadership initiatives.

There is a need to enable this first group of families and their supporters to achieve. They are early innovators and will be able to hopefully support others if their plans come to fruition.

Also with the emergence of Person centred thinking to look at how services are really using the training that they have already had to address change at an individual level, for organisations and the community.

There is a need to look at new sources of funding for learning opportunities for families - possible Learning Skills council and carers grants.

Next Steps

On the last day the participants from this course, senior managers, development managers and the allies identified what they wished to happen next. This was set in the light of new guidance to Partnership Boards regarding supporting families to lead person centred planning.

The dreams that people wished to pursue specifically regarding supporting families and PCP are

A real depth in choice
Everyone having a meaningful PCP if they want
People planning the way they want
All reviews to be person centred
Lots of facilitators who receive training to support families
Lots of families who are able to lead plans and act as mentors for others.
Lots more families leading plans and the plans are put into practice and lead to real change and not just talk
Attend FLP UK gathering 2006
Self advocates delivering training with families

People felt that it should be Positive and Possible in One Year to do the following

Families have developed plans and achieved some goals and dreams
More families are planning
Support for families to take the lead in planning
On going support for families to lead planning
There are local family support networks
Families and self-advocates are working with services to train other families and advocates

Workshops bringing together families care managers and support staff
To see families mentoring other families to plan
Lots of courses going on for families
2 more courses are ran for families to lead planning
Evidence of positive change in peoples lives that enable families to see
what's possible and that they then will want to do PCP

To stay strong people need to

Continuation of support to implement, write and support to keep the plan
live and evolving
On going support
Need to hear the good messages that it's working
Time to celebrate and share
Partnership board support
Keep in contact
Stay focused

Next Steps

Secure funding for FLP group
Expand this opportunity to others families
Help and support ethnic minority groups - translating materials
Identify funding for further courses
Review PCP strategy in light of new families guidance
Make sure all the families are connected from this training
Help other families to do this
Commitment form all concerned

Conclusion

Coventry and Warwickshire is on its journey of commitment to supporting families to learn about Person Centred Planning. It now has a small group of family members that have experienced developing Essential Lifestyle Plans for the people that they love. Through on- going commitment from the Partnership Boards it is now possible to identify ways in which this initiative can grow in Coventry and Warwickshire so more families have opportunities and people can work together to make change happen with and for people. This in turn will generate new learning for Coventry and Warwickshire and enable the Partnership Boards to start to meet Valuing

People's aspiration of *"... increasing numbers of families that can share positive stories about how they were trained and supported to plan and that services welcomed their planning and were flexible and responsive, and that their lives have changed in a positive way."*

Alison Short 14.3.05

