

Putting People First:

Planning together – peer support
and self-directed support



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Introduction

As councils look to develop new and more empowering relationships with people who use their services, finding effective ways of teaching people the skills to design and manage their own support arrangements, is becoming increasingly important.

Engaging people as active participants in support planning is key to enabling them to direct their own support. It gives people the opportunity to design and build their own solutions to their support needs, based on what is important to them.

The National Centre for Independent Living (NCIL) recently produced a report highlighting that the availability of effective peer support is essential in the transformation of adult social care and in enabling people using services to have greater choice and control.¹

This report builds on that premise, summarising activity undertaken as part of the Putting People First Delivery Programme's *Planning Together* project in 2009. It shows how it is possible to build disabled people and carers' own support planning skills, rather than continuing to rely solely on professional solutions to help people direct their own care and support. The report showcases examples of councils working in partnership with local

people using services, user led and other voluntary organisations, to transfer these important skills to other people who use services. The report was developed in partnership with eight councils who, with a small amount of seed funding were able to develop innovative ways to transfer support planning skills to people using services and build capacity for alternatives to formal support from professional care management. In some cases, developing these skills through training and other means has increased the number of disabled people working as support planners, in others it has led to people being empowered to take greater control of managing their arrangements with less dependence on professionals.

What do we mean by Support Planning and Brokerage?

The terms 'support planning' and 'brokerage' are common currency in social care but are sometimes used in different ways. Broadly speaking, within the context of personalisation, they are used to describe **the assistance that people need to work out what their choices will be, and the**

¹ Peer support and personalisation can be read in full at www.dhcarenetworks.org.uk/Personalisation/Topics/Latest/Resource/?cid=5962 or on the NCIL website.

support required to make it happen. For a fuller definition, see Department of Health guidance *Good Practice in Support Planning and Brokerage*, 2008.

Councils implementing self-directed support have so far been over-reliant on professional staff to help people plan and direct their care arrangements. The ADASS survey *Putting People First: Measuring Progress* published in May 2009 found that just 22% of Authorities had engaged user and or carer led organisations in the delivery of support planning and brokerage to all service user groups, while only 18% were extending these services to people funding their own arrangements (i.e. without a Council funded personal budget).

Current Department of Health guidance suggests that a sustainable approach to delivering support planning and brokerage needs to consider a number of different approaches to developing capacity. This is built on the premise that while some people will require the skills of a trained broker, others will prefer to source support from community based organisations they know and trust and others may only need a small amount of tailored help, perhaps from peers, to learn the skills they need directly. This report suggests that building capacity for support planning and brokerage is best achieved by investing in user-led organisations (ULO), community groups and networks and people using services and their families.



The lack of a strong user led culture within a given area and/or the absence of a lead organization with whom to develop these approaches can be a barrier. The 2009 Local Authority Circular: Transforming Adult Social makes it clear that overcoming such barriers should be a priority and the examples below offer some cost effective methods for doing so.

An enabling framework to ensure people can exercise choice and control with accessible advocacy, peer support and brokerage systems with strong links to user led organisations. Where ULOs do not exist, a strategy to foster, stimulate and develop user led organisations locally.'

(LAC (DH) (2008) 1

The following are extracts from conversations with people who participated in the *Planning Together* project in 2009 reflecting their journey towards building local partnerships with people using services and their carers to develop support planning and brokerage capacity. These extracts make clear the commitment to transferring skills and to building capacity within local communities and user and carer led organisations, which sends an important message that personalisation is best built together.

“It gave us the opportunity to formalize our partnerships – we moved mountains in a short space of time”

Emma, People First

“I felt proud of the authenticity of the co-production right from inception. It focused peoplespeople’s minds and we have built future capacity on the basis of this.”

Jane, ULO

Who is this report for?

The key aim of this report is to encourage councils, User Led Organisations and other third sector groups to work together to build a broader range of support for people to direct their own care arrangements.

As councils continue to develop their Transformation Programmes, the following

examples highlight effective and low cost ways to strengthen partnerships with people using services and carers and harness their expertise in designing and delivering support to people who need social care.

Key principles

Although it is difficult to describe best practice at this relatively early stage of development, there are nevertheless some strong themes emerging that are worth sharing.

Some key principles for developing individual and community capacity to support people to self direct.

- 1) Grow your own co-production networks:**
Local environments vary considerably and there is no “off the peg” solution to building local capacity. Building a local community of interest around coproducing support planning and brokerage with people using services, carers and their organisations is a great first step.
- 2) Councils and User & Carer led organisations need to be proactive in building partnerships around personalisation:**
Councils should aim to build capacity within local organisations to support the development of the personalisation agenda and the delivery of support for people to self direct. Councils should consider using part of their Social Care Reform Grant to this end.

3) Co-production doesn't just happen:

Genuine co-production needs leadership and investment in order to happen. The best examples we encountered were from areas like Redcar and Cleveland which established a team with clear responsibility for co-production.

4) Small steps can make big changes:

Investing in user and carer led groups as key partners in delivering support, builds the trusting relationships required for personalisation.

5) People feel empowered by being supported to learn and use support planning skills themselves:

Feedback from people using services and carers we received, suggested that transferring support planning skills can improve people's sense of purpose and control and can also lead to paid employment.

The remainder of this report is comprised of a series of accounts taken from those councils, ULO's and other partner organisations who participated in the *Planning Together* project, including two detailed case studies from Redcar and Cleveland and Derbyshire and some stories from people who went through the process of learning and utilising support planning skills. Together they represent a snapshot of some of the best efforts people are making to build an inclusive network of support to help people direct their own care.

Summary case studies

1) Walsall – The SPEaK Partnership (Support Planning, Empowerment and Knowledge)

In Walsall, the council, People First, Walsall Service Users Empowerment and Walsall Disability Forum created the SPEaK Partnership.

The SPEaK partnership co-produced training around support planning for two specific roles – champions and enablers.

Support planning champions

Support planning champions will be the founding group of trained people using services and carers equipped to train their peers in support planning. Their main role will be to deliver training to volunteers who come forward to take on the role of support plan enabler, offering peer training to suitably equip those volunteers to ensure there are people able to assist with support planning across Walsall. The second part of the role will be to offer drop in sessions, for people using services and carers and to support individuals in the planning process themselves.

Support planning champions will be recruited through a local advertising campaign targeting people using services and carers from the user led organisations involved in the SPEaK partnership. Walsall are hoping for an

initial cohort of six champions depending on suitability of applicants.

Support plan enablers

This will be a group of individuals, who once trained can be accessed via the SPEaK partnership organisations, to offer direct assistance to those completing support plans.

Training

This capacity will be developed through a staged and modular approach to training, taking into account varying learning styles and needs of the individual champions.

There will be an initial two-hour induction session which will allow the champions to meet one another and those involved in the SPEaK Partnership. It will include an overview of the course content, a timetable for delivery and an information pack.

The training will be broken down into three short days (10 – 3.30) to cover the various modules.

Support

Once trained, champions will be supported by a mentor who they will meet quarterly and through optional coaching sessions and facilitated action learning sets at agreed intervals.

What people said

"This has been absolutely fantastic and will enable me and people in my situation to lead a full life"

Anne, service user

"It has been really enjoyable. I am proud of the name SPEAK. This stands for Support Planning Empowerment and Knowledge"

Paula, Development Consultant

"We have been hammering at the door asking for a part in shaping services and this was a way in"

Roger

2) Brighton and Hove – connecting person centred planning with support planning

The partners in the Brighton and Hove work were the Federation of Disabled People, Carers Centre, Amaze, Circles Network and Brighton and Hove City Council. They set up two events – one for care managers, and one for people using services and their families.

The first event was for care managers and other stakeholders who may be supporting people to set up personal budgets within the next year. It aimed to increase local knowledge of Self Directed Support (SDS) and how people make their personal budgets work for them. There was also a focus on establishing SDS champions across Brighton

and Hove and giving care managers and other stakeholders a voice in the development of a local SDS Strategy.

The second event spanned 2 days and was for people using services, parents and carers who were looking to set up personal budgets for themselves or their loved ones within the next year.

What people said

"This gave us the opportunity to make the connections between person centred planning and support planning. We got fired up about what this can mean for people."

Nicola

"We turned the project around in short time frame and changed the attitudes of professionals"

Henry

3) Redcar and Cleveland – working with communities through the Copro team

In Redcar and Cleveland the 'Copro' team was established to co-produce support planning. The team included two community champions, the personalisation lead, the direct payments co-ordinator and a worker from each of the two local user and carer led organisations (Carers Together and Redcar and Cleveland Real Opportunity Centre – ROC).

The team decided that the community champions would take the lead in delivering support planning training with support from the team. They developed a pack that included a support planning graphic, person centred thinking tools and the planning guide 'In the Driving Seat'. The materials were made in large print, Braille and easier read.

Training was offered to a diverse group of people in order to be consistent with their citizenship ethos and their desire to move beyond the traditional silos of health and social care and beyond the labels of user and carer groups. One of the rallying cries of the group is 'tickets take us places (labels just stick)' and their work epitomized this ethos.

Each person who attended the subsequent planning events had an indicative budget. The sessions were based on the 'Planning Live' model where people are supported to develop their support plan over two sessions. Ten people developed their support plans using this approach.

What people said

"I loved the degree of trust that developed throughout teams and relationships, and the learning and richness that came from this. It has been a partnership that delivered some really positive outcomes"

Debbie

"I was proud to be invited to join the team"

Mary

"I was proud to be part of this total transformation of social care. It was excellent that the training involved a diverse group of people."

Linda, parent/carer

"I am pleased with the way that organisations have come together to learn and share"

Sue, carer

4) Shropshire – four courses on support planning

Through their involvement in the *Planning Together* project, Shropshire co-developed for courses around person centred approaches. These included:

Course one: Looking after yourself

A workshop for carers who are supporting and caring for a family member recently diagnosed with dementia.

A pilot of four two hour workshops took place. These were:

- 1)** What is dementia?
- 2)** Communication and dementia
- 3)** Looking after yourself
- 4)** Managing changes

**Course three: Person centred approach:
What does this mean for me?**

A three day workshop for people using services with learning disabilities who attend with their support workers to explore person centred processes, values, rights and choices and how to communicate their needs and wishes.

A three hour module of this programme will explore and put into practice the active involvement of people using services in designing the support planning and review processes.

Course four: Play your part in planning your support

A workshop for older people in day services to identify what is important to them, what they want to achieve and the support they need to do this.

This three hour workshop will result in a recorded support plan for each person.

What people said

"I am proud that through this work people with learning disabilities have been redesigning how their reviews take place, and the documentation about support planning, and have started training managers about this."

Christine

"I am proud of getting carers together – it has been an amazing experience from both sides."

Marion

5) South Gloucestershire – 'planning for dreams, not just needs'

Livestroughfriends worked with staff from Paul's Place and South Gloucestershire Council to create a five day training event that supported sixteen people to acquire knowledge and skills to self direct or help others to take control of their lives. A co-production planning day was held to design the events.

The events included:

- Helping people to think of a good life
- Creative and effective thinking
- Exploring personalisation
- Relationship network building
- Resource mapping
- Personal responsibility/self reliance
- Hearing from the council about the systems they have in place

This approach got people very engaged in thinking about what really matters in their lives. It helped people to think beyond money and services and to draw their own conclusions about what, "I really, really want".

The events enabled people to gain some first-hand experience of structured creative thinking and problem solving. The sessions included an informal “peer learning set” around participants’ personal support planning issues.

What people said

“I am proud of how people we work with have started to grasp this new way of working”
Colin, Livestroughfriends

“For the first time in my life I understand what people are talking about and I can see how it could work for my daughter”
Bridget, parent carer

“This project has inspired me – for once there seems to be a choice out there.”
Kevin, service user

“What we have now in South Gloucestershire is a group of people who can shape from the bottom up and hold the council to account”
Bob, Livestroughfriends

6) Derbyshire – exploring a range of approaches to support planning

People with learning disabilities and their families in Derbyshire worked together with MacIntyre and Derbyshire County Council. Together they developed and tried a range of

approaches, based on their experiences of person centred planning. These included:

- A group of friends and family working with a big support planning graphic and helping one person to make their plan
- A mixed group of individuals and people working across services learning about support planning together
- “Planning Live” with people and their supporters
- Working in partnership with the council training section to make sure information was consistent and reliable
- Working with people who use day services to plan how training should look and to begin to develop their own plans
- Working with citizen leaders to develop training content and delivery

What people said

“It has given a real kick start to take co-production seriously in Derbyshire”
Kathryn

“I am proud of the assessor training that we have been doing for 500 staff and how people who use our services have been training alongside us”
Sue, trainer

“I am proud of writing in the Derbyshire Times”
David, service user

7) Stockton-on-Tees – sharing information individually

The partnership in Stockton-on-Tees included the support agency for direct payments (A4E) and the council. They developed a training programme for people to learn about support planning and to become peer supporters. The aim was to utilise the direct payments people using services network to deliver the training.

The training was developed with people using services and carers and adapted based on their feedback. It comprised of ten hours of activity divided into hourly modules. These are delivered in individual units or in full days depending on what works for people.

The training programme was found to be very useful on an individual basis and could also be delivered to small groups of six to eight people and has become a further important role for the direct payments team.

What people said

"I am proud of the way it has been coordinated. We brought in additional funding to support this and make it real."

Peter

"I am pleased with the awareness training that we have been able to do – and how support plans are changing peoples lives"

Kelly, direct payments worker

"Stockton have been practicing what they preach with people and departments working together"

Mike, Education

8) West Berkshire – working with ULO's to create local champions for support planning

In West Berkshire, the council worked with user led organisations to co-design and deliver a three day training event. The partners included:

- Princess Royal Trust for carers
- Disability Alliance
- ROCC (Voluntary sector training provider)
- Neurological Alliance
- West Berkshire Council

The purpose was for people from local ULO's to develop skills and understanding around support planning and self directed support, and for twelve people from a range of ULO's to be developed as champions. There are different roles these champions will have in their organisations, ranging from signposting people to local resources or support to directly assisting them to plan or working to build wider local awareness and momentum.

The training that was developed covered issues such as:

- What are the differences and similarities between support planning and person centred planning?
- What does 'outcome focused' mean?
- What makes a good plan?

The sessions included people using services sharing their own plans and experiences.

After the first three-day course, people were invited to a 'Planning Live' session where they could get further experience in assisting people with support plans.

What people said

"I am most proud of the involvement with customers in planning and delivering this work"

Laura

"I am pleased about the concept behind this, sharing information, people become experts and then sharing it out across West Berkshire"

Appendix 1: Detailed case study – Redcar and Cleveland

Making it personal – Coproducing Support Planning in Redcar and Cleveland

Redcar and Cleveland Borough Council has developed and piloted a model of community-based support planning as part of their work to encourage self directed support through their “Making it Personal” programme. This programme is the council’s response to the transformation of adult social care and has been set up to “deliver excellence in outcomes” for people through personalisation. The council’s head of Adult Social Care Lynn Johnson said achieving this was only possible by working with disabled people, activists, citizen champions and carers to redesign systems and processes and begin to address the massive culture change of Putting People First.

A team from the council, alongside two citizen champions from the council who had undertaken Community Leader’s residential training through the North East Self Directed Support Academy and representatives from two local user and carer led organisations, put together a bid for funding to develop support planning skills with a diverse group of people using services and carers so they could share their knowledge, skills and experience to help others develop their support plans.

The plan was to have two, three hour sessions with eight local people who already have experience of having a direct payment, and/or who have experience of training in disability awareness or peer support programmes. This was based on an approach called Planning Live, and using materials from ‘In the Driving Seat.’ Following these sessions, the group would review what they had learnt to agree a model of coproduction that will inform future commissioning.

The intended outcomes of the pilot were that people should have the confidence and skills to develop their own support plans and make them happen and help others to do the same. Through review and evaluation of the pilot a community based model/models shaped by experts by experience in support planning would inform a commissioning proposal for sustained investment.

Who was involved and how we worked together

The coproduction pilot development team included two community champions, the council’s personalisation lead and direct payments coordinator and a worker from each of the two local service user and carer representative organisations – Redcar & Cleveland Real Opportunity Centre (ROC)

and Carers Together.

Jane Reast, ROC's Director, said it was really important to work with a diverse group of people on this project.

"One of our local rallying cries over the past two years has been 'tickets take us places, labels just stick'. (We wanted) to be consistent with our citizenship ethos and desire to move beyond traditional silos of health and social care and beyond the labels of user and carer groups that have often marginalised people who use services from each other."

Jane said the coproduction team agreed to pilot the work with seven people who already had a direct payment, and one of the community champions. Everyone who was contacted was enthusiastic and keen to be involved. They all completed an initial self assessment using a tool developed by the council. This provided the additional benefit of being able to feedback on how successful the tool was. The team's direct payment coordinator met with everyone individually to explain the project in more detail. Separately, and based on the results of the self assessment tool, they also developed an indicative personal budget available to support each individual, and this amount would be given at the end of the first session.

Jane said that the location for the sessions was "an important ingredient for a successful co-production learning environment" and the team was able to book a local hotel in a parkland setting. All expenses were included for the participants and materials in a personal folder made available in appropriate formats

including large print, easier read and Braille. These folders included a range of support planning tools including *In the Driving Seat*, *Life Planning* graphic, *What's Working and Not Working*, a self directed support planning jargon buster, a support planning scenario, *7 Keys to Citizenship*, *What Makes a Good Plan*, *7 steps to being in control of my support*, *Support Planning for Outcomes*, and the In Control DVD *How to be in control*.

By the time the day for the actual first session came, the coproduction pilot group included a diverse range of 'experts by experience' including carers and parent carers, people with physical and sensory impairments; and people with a learning disability and mental health needs.

The Sessions

The first session was held in late May 2009. Jane said that when everyone arrived, there was an air of anticipation and excitement mingled with a little fear and panic. But she said the overall feeling was one of friendliness as everyone met for the first time.

"People's anxieties were soothed with a few reassuring words or a listening ear," she said. "Connections were made where there was none before and the trust word was uttered even before the 'curtain' rose."

According to feedback on the day, the hotel setting did a lot to relax people, especially the view from the hotel and the smell of fresh coffee and croissants.

Community Champion Linda Dickinson got the day off to a start with introductions and laying out the ground rules – ensuring everyone understood the need for confidentiality and respect. She explained that over the course of the day, participants would hear a few real life stories and be shown example support plans, while then having the opportunity to start developing their own. Fellow Community Champion Barb Rankin also gave a presentation on “What is self directed support?” and showed a DVD of personal stories.

The participants had lots of questions including how long their plans would be for; when it will be reviewed; what would happen if someone lacked capacity and what would happen if individuals disagreed with their allocated budget. Other discussion took place around how people's spends would be audited; how to be creative in thinking about options for support and some tips for focusing on dreams and aspirations without feeling guilty about making choices.

The group divided into two working tables to start developing a hypothetical support plan for “Helen”. People were asked to think about what was working and not working in her life, based on the scenario Barb and Linda provided.

“Our timetable was hopelessly out but rather than stifle discussion, we were able to adjust,” Jane said. “The feedback we had during the first session was lively and animated. You could tell the confidence of some people had grown after just an hour together.”

Towards the end of the first session, each participant was given their indicative personal budget in a sealed brown envelope. “There was a sudden and palpable silence as this information was absorbed,” Jane said.

People were asked to begin work on their own support plans using different person centred thinking tools – the main ones being the support planning graphic and the most powerful of all, What's Working and Not Working? People were then asked to come back to the second session, held a couple of weeks later, to share their thoughts and ideas. People were also given a contact number at ROC for any support they might need between the sessions. Any support needed would be passed to the appropriate coproduction development team member.

The coproduction development team regrouped after the session to think about what went well and what they had learned. They agreed that the setting worked, the materials were useful and that people felt they had been engaged as ‘experts by experience’. “Trust had been established and fears had been allayed,” Jane said. “We were all resources for each other and no one was blaming or judging... just people's confidence and skills had grown. We too felt braver!”

The second session was held in June 2009 and everyone came back to share what they had learned about co-production and support planning. They started by reviewing how they felt about the first session. Some of the quotes from participants included “co-production is valuable – brings other

perspectives”, “very individual” and “harder to do on my own”. Others said they appreciated sharing ideas, talking, listening and learning from others while discovering the outcomes they wanted to fulfil by “prioritising my way”.

Next the group split up to continue the job – in pairs, groups or alone – to start thinking about how they could make their life plan happen. They used in Control's *In the Driving Seat* tool to find out how they could get support from each other to make things happen and to find any gaps in their plans and how they might be filled. Everyone also looked at how to make their support plans SMART by developing actions that were specific, measurable, achievable, realistic and time bound. They did this by considering what time, money, support, skills, experience, knowledge, communications and capacity was required to make their life plans work in a way that was sustainable.

Finally the group came together to think about what the best part of co-producing support plans was. People said some of the best things was the “learning and sharing”; “being able to open up”; having “open and empathetic support”; “sharing experiences”; having the “time and space to think” and the “opportunity to give back and support other people”. The only comment about the worst thing about the sessions was that someone felt the process would have really helped their dad be in control at the end of his life.

People needed more time and wanted to have the opportunity to involve friends, family members and supporters if this would help.

Where next?

A third session was organised in July 2009 and some people came with their significant others as part of their circles and networks of support, recognising the impact their plans would have on their lives too. This helped to encourage a new sense of giving oneself permission to have a life. Supporters included friends, partners, family and personal assistants.

Support plans were fine tuned and the next stage of having the support ‘signed off’ by the council was described. The prospect of another hoop to jump through was received with some concern. People were concerned that they would be judged and have to justify their plans – in effect their lives, having only just liberated themselves to consider a life!

People were reassured that whilst the prospect was daunting the Support Planning Agreement Group (SPAG) was also part of the learning for all and a must do for councils. It was also explained that this was different from care management in that people already have their indicative budget and have the opportunity to present their plan (with support if needed or wanted).

The SPAG group comprises an operational manager for adult social care, the review team manager and the direct payments coordinator. As this is a learning experience, commissioners of adult social care and finance officers also observe.

The SPAG group experience has been very powerful for all concerned. People have felt listened to and heard in relation to their lives and

aspirations and officers have heard first hand from people. Barb Rankin said it was very different than being “done to” and got some additional ideas about equipment that might help her.

The team have also developed a proposal to continue with a community-based co-production and support planning collaboration which will run until March 2010. This proposal has been agreed and there is now a community based support planning team that includes Community Champion Linda Dickinson. The team is overseen by the Copro support planning steering group that now includes two of the pilot cohort of people. The team works one day a week and is managed by Carers Together and ROC.

Jane said that now even more people will have an opportunity to develop their support plans in this way. She along with her colleagues in Redcar and Cleveland are thinking about how best to do this in a realistic and sustainable way, “Potentially for 1700 people by March 2011,” she said.

The coproduction steering group has expanded further to include a local *Staying in Control* pilot for people affected by dementia; and have met with local *Individual Health Budgets* pilot leads to share the learning, raise awareness, and as Jane said, “join up some more dots!”

“Carers Together and ROC staff are really enthused and keen to keep engaged. We’ve kept people in the Disabled People’s, Learning Disabilities and Carer’s Partnerships in the loop about the developments we’ve made. The council is exploring the possibility of

preparing a proposal to rise to the challenge of being a *Right to Control Trailblazer* which has the potential to widen the scope and breadth of funding to further increase choice and control for disabled people.”

Barb Rankin, Gordon Mogg and Jane have recently extended their experience with the council’s Action Learning Network – senior social care practitioners. They have described the work of the coproduction support planning pilot and Barb and Gordon have shared their recent journey. Practitioners were challenged to consider what’s working and not working in their lives to get a real feeling of what this can mean for people. They are also working on some scenarios to develop support plans – some are planners and some have assumed a role described in the range of scenarios. The team feels they have influenced change and hope to continue to change practice.

What we’ve learned and the issues to be resolved

Jane said that through this work, the coproduction pilot group have identified that the local market needs to develop to meet the needs of people who have identified creative and individual ways to meet their support needs. The availability and quality of personal assistants is crucial, and work is being undertaken to map the market and find possible opportunities for coproducing the development of different types of support.

Another issue identified was that the Disabled Facilities Grant needs to be included in the

personal budget allocation. For example, appropriate toileting facilities, which would be a one-off capital investment, would offer far more independence and dignity as an outcome, and be more cost effective than a PA. A way forward for one family has now been found which will make a huge difference to them.

The team is keen to let commissioners know that support planning underpins authentic self directed support. A key message is not to underestimate this or to assume that support planning also includes brokerage and implementation of plans. They are linked but distinct!

Helen Sanderson Associates are working with participants in the pilot to adapt 'In the Driving Seat' to make it more suitable for carers. This will be available on www.supportplanning.org.

Jane said she is excited about the next phase of the work, "this modest investment has catalyzed change and given a momentum that has energised us all!"

People's stories

Alison's story (the perspective of someone with a visual impairment)

Alison currently receives direct payments and has a personal assistant to support her with the tasks she finds difficult to manage because she has a visual impairment. In the past year, Alison has been working within a

pilot coproduction support planning team to create a support plan to help receive a personal budget. This will help her to have more flexibility and control with the funding she receives. Alison's support plan was recently reviewed by a panel and has since been approved.

Alison is in her 30's and is a qualified secondary school music teacher with dreams of one day owning and running her own music school. Alongside her passion for music and writing songs, she also suggests she is a closet Harry Potter fan and has recently taken to collecting reborn dolls. Alison has been visually impaired since birth and has raised three children with her husband of 10 years, who has been visually impaired since his teens. After the death of her father and the birth of her second child a number of years ago, Alison knew she had reached a "make or break point" and contacted the council for help.

"With so many changes happening at once, I knew I needed help now, right now," Alison said. "I didn't think they'd be able to help, as I thought I had to be quite bad, but the kids and changes were just too much...at times a three year old can make you feel so small and intimidated."

The council mentioned direct payments to Alison after hearing about her situation, and passed on contact numbers for the appropriate people in social services. A member of the social services team met with Alison and discussed her situation and her need for an assistant. "I didn't want someone in the house to look after the kids; I needed

to find someone to support us in areas like keeping the house tidy and safe for the children, and to help us with shopping and taking the kids to the park. I didn't want my mum to have to be around to help all of the time either, that isn't a situation I would like to put her in, she needs to enjoy the grandchildren and come when she wants like other mothers do," she said.

Alison began receiving direct payments so she could employ an assistant to help with the established needs of shopping, cleaning and helping her to give her own children the experiences that sighted parents take for granted, such as playing ball, using computer games, doing homework tasks and so on. Part of the process included a meeting with a personal financial guide from her local Centre for Independent Living, who explained aspects from a business perspective and also helped with completing financial forms. "He was great and really explained the financial side of things clearly. I was worried about employing someone and completing the forms correctly," she said.

Alison also met with the Sensory Support Group and a direct payments coordinator to assist her with organizing employment, managing her payments and looking at other areas of her entitlement.

"All of the professional experiences have been wonderful...very positive and empowering for people," she said. "I didn't find (the process of hiring an assistant) easy, but I learnt from my mistakes and remained positive. It was, throughout the process,

lessons in life. I knew the monetary support was now in place, so it was just the challenge of finding someone. I wanted to maintain a high level of independence, but needed help with checking food dates and quality of food to ensure it is safe to eat, and also changing dirty or unsuitable clothing when I am informed of stains and holes etcetera."

Alison has been working closely with her assistant for three years now, and has noticed an improved quality of life and greater independence. "The direct payments have certainly made a difference. I feel more of a stable person, I felt so isolated before" she said.

Earlier this year, Alison was asked by a member of the coproduction pilot steering group if she would like to participate and be involved in a pilot for personal budgets. This would involve her attending Coproduction support planning meetings, based on a process called Planning Live! and creating a support plan that would deliver the outcomes she was seeking.

Alison said her motivation to participate was because "...they needed people from various backgrounds with various disabilities, and I liked the idea of personalised payments, having more control of the funding and using the money for what I need."

The Coproduction meetings were set up as a way for the members of the personal budget pilot to meet locally and discuss the process, and gain support and learning from other members while creating their individual support plans.

“At one of the meetings, we were shown a DVD about direct payments and about people who receive them and have successfully made the transition to personal budgets and the difference it has made to them. However, the biggest impact was the hypothetical story that was handed to us on a piece of paper. It showed a scenario about a person with a disability who received direct payments, and their hypothetical goals and dreams. It asked us to answer questions like ‘Would we think it was ok for them to spend money on a mentioned situation?’, and it was a powerful teaching tool for me...I felt less guilty when creating the planning tools when I could look at this hypothetical scenario and compare it to mine.”

Alison also received help from her family and personal assistant when creating her support plan, with topics and questions including ‘What do you think you need help with; what’s working in your life now and what’s not working, and what things are most important for you?’ For Alison, these were things like positive constant parental involvement in the safe care of her children, what meals were planned and served by her, checking the cleanliness and quality of clothing, and shopping.

Alison’s advice to others is “...be as open as you can be with the people putting the plan together, because if you get it right you can get the support when you need it the most. Don’t be afraid to challenge what they are saying either. If you have a need and it is not being met, ask why it is not being met. It’s not enough when they say they can’t help,

the point is to empower people. If it isn’t working one way, it is their duty, and yours, to look at another way. You’re in control of changing it.”

Recently, Alison’s support plan was submitted to a panel for a review, along with other members of the Coproduction pilot team. Her plan has been approved, and Alison will now receive a personal budget. “I’m sounding out the possibility of owning a vehicle for my family, and hiring some assistance to help me move furniture in the house and with the maintenance of the garden, the guide dog area and erecting play ground equipment for the children,” she said.

Alison added that the support she has been receiving has made a “dramatic difference” to her life, enabling her to spend more time with the family, strengthen her social connections and focus on her passion for music and collectables.

Cath’s story (from a mental health perspective)

Redcar local Cath, 44, is receiving a direct payment to help provide support for ongoing mental health problems and physical impairments. As a member of the Coproduction Support Planning Pilot she created her own support plan.

Cath is very artistic with strong interests in poetry, painting and drawing: she is hoping to organise an exhibition to display her artwork soon. However for the past two decades, Cath has been receiving psychiatric treatment for mental health problems, and since 2000, she

has had muscular and immunity problems that have required continual physical treatment. In 2001, a social worker spoke to her about direct payments and explained how and why it would benefit her. Together with a social worker and a member of the local Centre for Independent Living, Cath completed a document that outlined her needs.

Cath said she was asked lots of multi-tasking questions: "...Things like 'how do you take care of yourself and what do you need at this time', and from a financial perspective, 'if I'm receiving direct payments and need to do tax work, hiring & timesheets, were there going to be complications?' I wanted to be involved...this was important to me. It was a long process because of my issues, but the social worker kept encouraging me."

Cath began to receive direct payments soon after this meeting, and was able to hire a personal assistant.

"I would definitely recommend direct payments to others; it gives you a sense of being in control...I felt safe receiving the direct payments. Even if I'm only doing paperwork, I'm still involved in something. Before I had to rely on people and things and I don't like to ask for help. For instance, if I have a panic attack and my legs are hurt, it could be late at night and I don't want to, or can't physically, ask for help. So to know I can hire someone who is going to be there for assistance makes me feel safe. My advice would be to try and get out and about and speak with people, your social worker. Look on websites for information, and attend meetings if you can," she said.

After years of receiving direct payments, Cath felt that she needed more independence with the funding. She wanted to be able to use the money to enhance her quality of life in other areas and required more flexibility and control over how the funds were used.

"I became frustrated because even though I was made aware of what the funding could be used for, I felt somewhat childlike when seeking permission to use some of the funds,...it did not give a feeling of independence, it felt like other people were making far more decisions than me and that I had little control. I needed more control," she said.

At this point, Cath said even though she was receiving a lot of good support from her social worker, she felt isolated and withdrawn from society and she was invited to be part of the local Coproduction Support Planning Pilot. The meetings allow people to share opinions and have a voice. People planned together using 'Planning Live!'

Cath explained that these meetings were a great way of her getting out and about and to have a voice. "Before I went to the meetings, people kept 'shutting doors' and I became closeted and stopped looking outside. Since I joined the Coproduction team, it has changed my life, I've invested myself into something and I have more drive. I'm meeting people, my depression is getting easier to cope with and my happiness has improved. Physically I have changed also, because I'm not focusing so much on my problems, I still have the symptoms, but its better."

Cath said her focus at the meetings was to let Social Services know that even though she had the money; it wasn't always easy to get the support she needed. "The money is restricted and it is very different to the flexible options that are ahead with personal budgets."

During the support planning process, Cath said she felt a lot was accomplished because she was encouraged to consider broader questions about her mental health, and didn't just focus on her physical state. Throughout the process, and to incorporate as much detailed information as possible, Cath kept in touch with her social worker and psychiatrist.

"My social worker has been an absolute angel, yet others are sometimes uneducated and are afraid of mental health. So when I need any assistance for housing etcetera, the authorities and other services used focus more on the physical aspect not the mental aspect. I believe that mental health is a disability, it has the same affect on my body and mind as the physical problems I have do and sometimes more, and the mind is as important as the body," she said.

The support planning process made Cath think about questions like 'What can I do?' and 'What's working in my life now, and what's not working?'. Some of the things she wrote in her support plan included:

- 1) "...advice is always appreciated, support always welcomed, and criticism always listened to."
- 2) "I wouldn't change my key support network of people for I trust them impeccably, and I am now feeling stable

enough to implement the changes needed to make me more happy."

- 3) "I don't have enough access to people around me, so I'd like to get on-line and be more involved and I have restrictions on my existing plan that holds me back from being as independent as I'd like to be."

Cath said she felt that personal budgets need to be given a fair go. "We're all learning, and for someone like me who has disabilities with agoraphobia and anxiety, to be this excited about the Coproduction team and the chance of payments changes...it's a big thing. I feel my job is to educate people and be upfront with people about mental illness. If you walk into a meeting or situation with a wheelchair, they know why you're there, but with mental health it is otherwise. If I can help anyone, it's something I'd like to do."

Cath said her outlook for the future now is positive. "At this minute, I'm on cloud nine, and even if the plan doesn't get signed off it's given me the chance to do something and meet a great group of diverse people all with different health issues, who have become friends as we have a common understanding in what's happening and we are all on the same journey. I was so stagnant, and am now so excited. It's been a wakeup call for me, and not only do I want to do art exhibitions, I want to do an internet course and set up meetings for mental health awareness. I want to get involved because I care."

The Coproduction team members involved in the pilot recently went to the panel and

submitted their support plans. Cath's support plan has been agreed.

"I'm going to give myself a year to set things up, though my goal is to move out of my house and either part own or privately own. I also plan to set up my art exhibition and begin writing a book. I am absolutely elated and if I could give one bit of advice from what I've learnt through all this, it would be live your dreams, not society's hopes."

Barbara's story

Barbara was the first person in her local area to receive direct payments. She has MS and is a trustee of her local user-led organisation. Barbara has been working with others to develop and deliver a way to co-produce support plans. Barbara's support plan was recently reviewed by a panel, and has since been approved.

Barbara has been married for 38 years to a talented Bridge player, has two children, she enjoyed an active social life and also spent time making crafts and corn dollies but now embraces the "therapeutic support" that her two cats provide on a regular basis.

Seventeen years ago, at the age of 49, she was working as a lecturer in IT and Communications but was diagnosed with a chronic and progressive form of Multiple Sclerosis which eventually forced her to give up work. Since then she obtained a postgraduate certificate in disability studies and has become extremely active within the

disability arena and is a trustee for her local user-led organisation: Redcar and Cleveland Real Opportunity Centre (ROC).

When Barbara was admitted into hospital after breaking her leg 12 years ago, she was told that she would never be able to stand or walk again. She is now totally reliant on her electric wheelchair and hoists. "When I was in hospital (outside the authority), I met a social worker who changed my life. He spoke to me about direct payments and enabled me to become the first person in the borough to receive them," she said.

Barbara worked with and had training from her local Centre for Independent Living, who encourage people to apply for and learn to manage their direct payments.

"It wasn't daunting and I gained the skills that enabled me to successfully manage my money," she said.

Barbara has successfully managed her own care, via direct payments, for the past eight years, with social services providing funding for care assistance. "I have seen some changes over the years", she said. "In the early stages, direct payments were simply for personal care....for someone to help you get up, have a bath, and get into bed. Not to help you go out and lead a 'normal' life. And just to show how naive I was, when I moved here 11 years ago, I didn't ask for social services assistance, and the money my husband and I had saved for holidays and other things was spent on installing a lift in our flat...I didn't know they could help."

Barbara has been proactive in her learning about personalisation and is one of two Citizen Leaders in the field to help and work with the council and partners to establish a more personalised and individualised system. “At the early meetings, discussions were about the benefits and how good it would potentially be. I’d then say ‘Sure, but when are you going to do it?’”

Barbara is part of the team that has developed and designed the local Coproduction Support Planning pilot where people can be a part of a group where they can discuss issues and experiences together and support each other to identify their needs and formulate their own life plans, then turn these into support plans. These meetings used a guide called ‘In the Driving Seat’ and followed the Planning Live! process where people met and developed their support plans together.

Barbara said for her, part of these discussions involved assessing how she was coping with the current direct payment system and care package and taking note of the disadvantages. For Barbara, her direct payments sometimes left her “... feeling like I always have to ask permission of others and fit in with them – there are too many carers, the agency have sent over twenty different carers for evening care, over last year; and (it is) not flexible enough – doesn’t take account of my changing/variable needs. My life should consist of more than care...”

“The meetings are very informal and often held at a local, friendly venue. New people who attend for the first time have been heard

to say ‘don’t know if I can handle this, (in a shy tone)...and then they return the next week and stand up confidently and have their say. People at the meeting often say ‘yes, we hadn’t thought of that’”, she said.

When Barbara is approached by people in the community about direct payments or personal budgets, her advice is “to speak with their social worker, local organisations or disability groups or independent living centres. Personally, I’d send people to ROC, as they have become a central point for info for disabled people. I would also suggest attending any meetings regarding the changes or future of the social care system.”

She adds, “(direct payments) put you in control of your life, if you feel you can manage it. I understand it’s not for everyone, but if you feel you can manage it, you should. It has totally improved my quality of life, I wouldn’t be here in my home if I hadn’t been told about the direct payment scheme, I’d be in a care home. I also know of younger disabled people in their 20-30’s who would have been ‘put’ in a care home if not for direct payments”.

“I spent many hours on the support plan..., and have had a lot of support from family, friends, carers and professionals, as well as attending training courses and workshops. Personalised payments will give me the different kinds of support that I, and my support network, consider that I need. It will give me and everyone else involved, the opportunity to be more flexible and proactive” she said.

Barbara recently had her support plan agreed by the local panel, which was a daunting prospect as she presented it herself.

Barbara explains: “This system is not set up to knock you down, but to give you the chance to make the panel aware of how life is for you and your family. The best part of it is there is recognition of a need to improve quality of life. It’s your choice. With personalisation, it’s no longer a social worker telling you what you want; you’ll be receiving money to do what you choose to do with **your** life.”

With Barbara’s plan approved, she will now be able to visit her elderly mother (90) who lives 200 miles away, and her personal assistant will now receive physiotherapy training to enable her to help Barbara with much needed exercise.

Gordon’s story (a carer’s perspective)

Gordon works full time and is a carer for his wife Kath, who has Multiple Sclerosis. Gordon and Kath have been married for 30 years; they have two grown sons and a very lively dog. Kath has been receiving direct payments for a few years, meaning they could hire a personal assistant to help Gordon care for her when he is at work. However, Gordon still experiences difficulty with managing his work and caring commitments as well as finding time for himself. Gordon has developed a support plan so he can get a personal budget, which he hopes will allow more flexibility with how they spend the

money they receive for Kath’s support while providing a better work, caring and life balance.

Kath was admitted into hospital two and half years ago after a sudden relapse and has been immobile ever since. During that time, a nurse approached them about options with social services and direct payments that could assist them once she was discharged and ready to go home.

“We were given bad news about Kath’s condition,” Gordon said. “...This is as bad as it’s going to get...she can’t even get out of the chair, and it’s not always easy to take when you’re first out of hospital.” Gordon made contact with his local social services department to work out the kind of care Kath would need, and to start the process for receiving direct payments.

“When you haven’t been in a situation like this before, you’re not always sure what’s available and what’s needed. Not straight away. I initially had to take time off work and help my wife throughout the day, getting dressed in the morning and then with lunch and then going to bed. Now that we receive direct payments, we have an assistant that can help during the day while I’m at work” he said.

Gordon and Kath spoke with social services about the kind of support Kath needed and for how many hours during the day while Gordon was at work. Within a short time they were receiving direct payments and started the process of finding a suitable care assistant. “At first we received funding to hire an

assistant for 30 minutes a day to help Kath get ready in the morning and help around the house, then after a while we asked for a review because it wasn't enough time, and we eventually employed a carer for 1 hour a day. We do all the paperwork also...Kath is the employer."

Gordon and Kath faced a few hurdles when initially hiring an assistant, mainly due to the number of available and qualified people who were interested in working minimal hours per week when they could be offered better hours in a different care situation. They approached this problem with social services, and after another review of their plan and Kath's condition, they were offered direct payment support for the employment of an assistant for up to 18 hours a week.

"The assistant has given us both some independence and Kath feels less guilty, it's not only physical independence, it's psychological... it's quality of life," Gordon said.

"People still feel intimidated by making contact with social services, or feel guilty to ask for help. My point of view is that they are open and here to help. They are very helpful...it's just that there's not enough of them available to help."

There was a point in time when Gordon fell ill and had to take months off work, which also meant he couldn't care for Kath as much as was needed. He felt exhausted with life commitments and knew he had to find more support to help around the house and also find time to relax and do the things he enjoys

doing. When he had recovered, he attended different local meetings for support and to gain information.

Gordon recommends the first step for carers in similar situations is to contact carer organisations, contact social workers and talk to people: "I attend our carer's partnership meetings, every quarter, where carers come together and have their voice heard. You hope that your experiences can help someone else. There are many people from the community there...PCT, chief executives and politicians...they understand that they are professionals but don't have a clue what it's like as a carer. The attitude is changing."

Gordon also got involved in the local coproduction support planning pilot. The sessions were held so that people could work together and learn and develop self directed support plans. Gordon found his opinions and feedback were really welcomed because he was coming from the carers' perspective.

Gordon and Kath worked with support workers and other members of the pilot from the local council, Carers Together and Redcar and Cleveland Real Opportunity Centre (ROC) to create the support plan. It involved a detailed discussion about Kath's current physical and psychological condition, including Kath's ability to dress and bathe, and how she was coping with changes in life at this time. It also involved finding out about Gordon's personal needs and wellbeing as a carer. He was asked questions such as, "How do you keep healthy and safe?" and, "describe a good day for you?".

His responses included “...playing badminton, bowls, walking the dog through the local park or on the beach, knowing my wife was safe and comfortable, and having more time to relax!”

Gordon said he found the process really useful and that he was looking forward to the flexibility offered by personal budgets. “... (It) will allow more control of how you spend your payments...gives you more choice. Kath likes to sit at the window and look outside and the windows are dirty and need cleaning...we want to be able to hire a cleaner to do those sorts of things,” he said.

Gordon said he is looking forward to experiencing the system evolving and supporting their need for ongoing independence and quality of life. “The idea now is to focus on all sorts of access areas around the house for Kath...the bathroom needs new fittings...and I want to be able to spend more time at home relaxing with Kath and make it to a game of badminton or golf every once in a while.”

Gordon’s support plan was one of the first to be submitted for approval by the local council and it was recently approved. He said his immediate actions included hiring a gardener; a cleaner to help around the house and clean the windows; and renewing his golf membership.

Appendix 2: Detailed case study – My Way Derbyshire

My Way Derbyshire: Using ‘Planning Live’ to develop support plans with Gemma and Kirstie



Gemma and Kirstie are friends and in their early twenties. They both live in Chesterfield and love socialising and music. Recently they have worked with Margaret, a facilitator from My Way, to create their support plans using a process called ‘Planning Live’. Through this they created a strategy that would enable them to move out of residential college, and live together in their own home with the support they need.

My Way Derbyshire is a partnership project between Derbyshire County Council and MacIntyre that provides facilitator support for young people who are in transition to adult life, and want to be amongst the first people in Derbyshire to use a personal budget. The

My Way facilitators work to make a support plan and help find different options with young people about where they might live, who they may live with, what they might do during the day and how this can be done flexibly and in the way that works best for them. Gemma and Kirstie were referred to My Way in 2008, as they were both seeking a change in their current living situations and wanted to move out of their family homes.

Gemma was the first to meet with Margaret, a My Way facilitator, and decided to create a support plan that would encourage Gemma to think about what she needed to move towards her goals and use her personal budget.

Gemma explains that the reason for creating this support plan is “so everyone knows how I want to plan my future and what I want to change and help me achieve this”.

Gemma’s support plan describes the changes she wanted to make and these included:

- “I want to move into my own home with a garden in Chesterfield, not too far away from my mum when I finish college.”
- “I would like to share with my friend Kirstie because I think I would be lonely on my own and I know that I will need support but I want to do my own domestic tasks including cooking and shopping.”

Kirstie was also referred to My Way around the same time as Gemma, and during her discussions with Margaret, she talked about what is important to her in the future, and these included:

- “Moving into my own place and sharing with Gemma.”
- “Living not too far away from mum and dad, and keeping in touch with my friends from college.”

Margaret suggested that they develop their support plans together, through a process called ‘Planning Live!’. Planning Live is a process where people come together, with their family, friends and supporters to develop their support plans. This can either be a couple of people (as it was with Gemma and Kirstie) or with up to 10 people and their allies, who develop their support plans simultaneously. This can take a couple of afternoons or a couple of days, depending on the group.

Margaret, Gemma and Kirstie used Planning Live over two afternoons to develop their support plans, think about living together as housemates, and to plan their actions.

Planning Live!

In preparing for Planning Live! Margaret's first step was to get as many people who knew the young women into a comfortable environment together, at an agreed time and place. She made sure they all had plenty of time put aside to share lots of information about what

is important to Gemma and Kirstie and how best to support them; and what they think a good day and bad day looks like. Margaret gave everyone a brief outline of what they would do so they weren't anxious and had plenty of time to prepare.



When everyone arrived for the Planning Live afternoon, Margaret had set the room up with two tables for each of the young women's' families, their support workers and care managers. She had pinned up some flip charts with headings such as “All about me”, and “What I would like to achieve in 12 months time.”

Margaret explains what happened next: “It was quite informal really. Each family in their own time came up and contributed to filling out the charts. Kirstie and Gemma were represented in different colours to emphasise their individuality in the joined up process. Both young women filled in all the information. I moved from one group to the other to facilitate and expand the information they were putting on the charts – for instance – if we needed some clear definitions or if some

of what they were saying was vague... When they felt they had shared all the information they needed to share, I brought everyone together to talk about what a day in the life of sharing a property together would be.”

During the Planning Live process the young women talked about what they needed in a property, including a spacious environment that would provide wheelchair access and personal space, and a location that is close to family and friends. “It felt like, for the first time ever, I have really been listened to,” Gemma said. Locating a property and formalizing the steps needed for Gemma and Kirstie to move took approximately two months, and involved working with housing and support agencies who would help find a property and the council who would help with funding the move.

Margaret said she checked if the young women would get on and whether there would be things that she and others would need to mediate. For example, one young woman wanted to have a dog for the disabled, so they needed to check whether the other young woman had any allergies or phobias about animals.

“It was about checking compatibility. We had a very light hearted discussion around interests, hobbies and the things that make people crazy like being untidy or very tidy and how that might work in a sharing environment.”

Margaret said the most important thing to remember during the Planning Live process

was to “listen really closely to what people are saying.”

“Double check what they’re saying is what they mean. Also, know from the outset this is a time consuming process. To get a good result, you need a lot of input from everyone. Let everyone know in advance that this is something they really need to get involved in.”

Because Gemma and Kirstie had an idea of the budget they were entitled to up front (their indicative amount), they were able to draw up an action plan of how they could find a property together. They created a set of actions to look at what sort of properties Gemma and Kirstie would like to look at, the areas they’d like to live in, the kind of facilities they would need and how much they’d like to socialise. The whole process took “a long afternoon” and the information Gemma and Kirstie provided became a checklist once their house hunting started. It made clear what they wanted to achieve so that later they could go back and identify where any compromises in the house hunting would need to be made.

Margaret organised follow up Planning Live! sessions to check all the information and look at the finer details. “We put together a handbook of the things they’d like to do and how they could do them.” She also arranged several social events with other young people so they could spend more time together to get to know each other more. The follow up meetings gave the families, support workers

and care managers time to meet each other and discuss the best strategies for helping Gemma and Kirstie move towards their goal of living together independently. It also involved reviewing their individual support plans so that the council could agree them. "I would recommend the support plan process to others, it is more flexible compared to the old care (with direct payments)," Gemma said.

Moving into their new home

As a result of the Planning Live meeting, Gemma and Kirstie looked at a number of properties and chose the one that best suited them and to work with Enable Housing Association to make this happen. Enable supported them to have their say in the layout inside of the property before they moved in, which included knocking down walls, choosing kitchen fittings and colour schemes.



In late August, Gemma and Kirstie moved into their new home and celebrated in a grand opening style surrounded by friends,

family, support workers, people from Enable and the facilitators.

"We had a cutting of the ribbon ceremony and a sign saying welcome to your new home. Family members came – mums, sisters, grandparents, people from the agency – the young women really enjoyed it... It's very rewarding to see them living in the property and looking happy and relaxed. It's given me a lot of job satisfaction." said Margaret.

Margaret said the best thing about the experience was that the results she helped Gemma and Kirstie achieve are more positive than the way things had been done previously, where it was "this is who is available" and "this is the person coming to you today and tomorrow it could be someone different".

"(The Planning Live Process) looked at every angle to ensure it was a positive experience for the young women. They were involved in every decision. They could choose who supports them, not just the agency. If they had any doubts, we'd work on them, work out what they were and reassure them and put contingencies in place. The entire decision (on where they want to live) has been theirs and we've just facilitated that for them so they can get what they want. It's been completely person centred the whole way."

For Gemma and Kirstie, life is very different.

"I was excited and quite nervous about the move, but I'm adjusting and now enjoying it. I get more freedom and time alone now," Kirstie said.

Gemma said she agreed: "My relationship with my family has improved, it's a lot better now that they're not having to help me all the time."



Now that Gemma and Kirstie have accomplished the goal of leaving home and moving to their own home, they are focussing on their other goals in line with their personal budget and support plans. These goals include being involved in local volunteer work and arranging in home physiotherapy equipment, as well as planning holidays abroad and attending more social events.

Gemma's support plan

(With many thanks to Gemma for kindly agreeing to share her plan!)

All About Me

- I am 19 years old. I am currently at residential college. I leave College at the end of July.

- I live with my mum, my dad and my sister.
- I have grandparents that I am very close to.
- I have recently had an operation on my spine and am recovering well.
- I have a bubbly personality and am always laughing, friends say "my laugh is infectious."
- I can communicate very well and I talk a lot; my friends say that it is sometimes hard to "shut me up"!!!
- I help my friends who are not as confident as me to let people know what they want.
- I join in with most clubs and activities at college and represented college as an Ambassador.
- I would like to represent disabled young people on a forum to improve services for disabled people.

Things I like

- I like listening to music especially drum and bass
- I like to meet new people
- I like to go shopping for clothes
- I like spending Christmas with my family
- I like trips to the pub and going to discos.
- I like to be pampered

Good day

- A good day for me would be to wake up in my own home, choose when to get up ,be supported to shower and wash and dry my hair, to choose some nice clothes to wear .
- Be positioned well in my chair which has been charged up and is ready to go.
- To be supported to prepare and eat breakfast.
- To plan a day out of my choice.
- To have a nice morning out or going shopping calling at a pub or café for lunch.
- Go to do some volunteer work and meet some nice people in the afternoon.
- Home to prepare an evening meal whilst listening to music in a wheelchair accessible kitchen, in my home.
- Chill out in my armchair watching a DVD with popcorn to eat with a friend and having a good laugh.
- Getting ready for bed at a time of my choice.
- Being supported to get comfy in bed to rest ready for another busy day tomorrow

Bad Day

- Waking up in my parents home
- Care staff from agency arriving to get me up before I am ready.
- Being rushed to use the toilet and my Closomat not working

- Being rushed to shower and not having time to wash and dry my hair.
- Someone choosing clothes for me to wear.
- Being stuck at home with mum getting under her feet.
- My electric wheelchair being broken so I have to rely on someone pushing me around the house.
- Not being able to listen to my music as mum doesn't like it on loud.
- Having no choice what to have to eat as mum has planned the menus for the week and I don't fancy today's choices.
- Having to wait for dad to get home to help mum put me in my armchair.
- My sister wanting to watch some sloppy programme on TV.
- Going to bed early because the agency have no staff any later than 9 o'clock

What's Important To me

- My family are very important, my mum has been my main carer and advocate and has helped me think about being independent.
- Roast dinners are important to me especially the way my Nan makes them.
- I have a lurcher called Tango "he is my sunshine!"
- I am a cinema buff and I need to keep up to date with new films.

- Going to discos is important to me as I like meeting people and I like the atmosphere and music.
- I like talking to new people.
- I need to be noticed and will never be a "wallflower"
- It's important to me to be able to get out and about in my home and in the community in my electric wheelchair.
- It is important to me to be helpful and supporting to others and make sure they are OK.
- It is important to me to have a lay-in at the weekends to recharge my batteries.
- It's important to me to sit somewhere peaceful in the fresh air sometimes, I like going to the canal near my home and seeing the swans and ducks.
- It is important to me to have holidays abroad so that I can relax and do some sight seeing.

What's Important to me about how you support me

- The best way to support me is to listen to me, I can tell people what I want.
- Respect my privacy and dignity – make sure I have all the equipment I need to do this.
- Support me to do my exercises so that I sit well in my wheelchair.

- Take me to the hydrotherapy pool to make sure I can stay fit.
- Make sure that I have a healthy diet.
- Help me plan my busy social diary.
- Help me to manage my money and don't spend more than I can afford.

What I want to change

- I want to move into my own home with a garden in Chesterfield, not too far away from my mum when I finish college in Mansfield.
- I would like to share with my friend Kirstie because I think I would be lonely on my own.
- I know that I will need support but I want to do my own domestic tasks including cooking and shopping
- I want to plan my own activities when I move back to Chesterfield so that I do what I find interesting and fun so I will never feel bored. I want to choose what to do, when to do it and who with!
- I want to do some voluntary work to help other disabled young people. I want to work at Shop Mobility in Chesterfield
- I would like to do some paid employment in the future, maybe in an office.
- I do not want for my mum to be my main carer anymore, I want to be able to visit my mum and dad for a cup of tea and for them to visit me in my home.

- I want to employ Lisa to support me.
- For the times that Lisa cannot support me, I want to work with an agency to choose the people who will support me and be involved in their recruitment.
- I want the people who support me to listen and respect me in my home and I want to make decisions, but I might need some advice sometimes.
- I want to be in control of my money.
- I want to be as independent as I can be.

Who will manage my support?

- 57 hours of support will be commissioned with Enable. I will hold regular reviews with my care manager to make sure that they meet their contractual obligations – doing what we have agreed. Risk assessments will be done to keep me safe and well.
- Health professionals will review the health funding with me.
- My mum is my appointee and will help manage time sheets and oversee my direct payment bank account.
- I will employ DCIL to manage the payment of wages, national insurance and tax.
- The provider organisation will manage the Supporting People funding with me to ensure that the time is tenancy related.

How will I spend my budget?

- I will employ Lisa as a personal assistant for 18 hours per week
- I will jointly contract with Kirstie for the provider organisation of our choice, Enable, to support us 57 hours per week:

Funding	Number of Hours	Hourly Rate	Total
YEARLY TOTAL			

Paid support

- hours 1:1
(hours for me and hours for Kirstie)
- hours 2:1
= hours total
+ 7 sleep ins

Unpaid support

- 5 hours project support each week for 4 weeks.
- 6 hours family support
- It is expected that buddies at my activities of choice will provide unpaid support after I have gotten to know them and settled in.

Additional support

- 6 hours outreach support for 6 weeks to help me find out what things I need to be

even more independent. I will use this time to concentrate on getting to know public transport routes in my new local area.

How will I manage my support?

- My mum is my appointee with my money at present but I would like to take control of a small budget each week to help me understand my money and not spend more than I have. I will ask Lisa my PA to help me with this.
- I will work with DCIL so that I understand where my money is being spent and what money I have coming into my account.
- I will be involved in doing budgeting for the shared costs in the house like food and cleaning products.
- I will be involved in my person centred review each year to make sure that I am in control of any decisions made about my support.
- I will be involved in regular house meetings to ensure that the support staff are working the way I want them to, particularly taking into account my privacy and dignity.
- I will be involved in supervision sessions for staff on an individual basis to ensure that our relationship remains good and identify any problems or extra training the staff may need to support me the way I want them to.

How I will stay in control

- I have chosen people to support me from a provider organisation in a matching exercise, based on their attributes and

interests. They have clear job descriptions and care/support plans as well as being able to listen to me.

- I have made a one page profile to show who I am and what I like, I will continue to tell them about my support needs and interests.
- I wrote the questions and my family and facilitator helped me to interview the people so that I could choose.
- If I need to recruit again I would always like it to be done in this way so that I choose who supports me.
- I am able to make decisions about my every day life and my future and have participated in my person centred plan and planning live sessions with my family, my social worker and My Way facilitator. My hopes, dreams and aspirations were taken into account. We looked at what I wanted to change and looked at how I could achieve my dreams over the next year.
- I have chosen where I would like to live, who with and who will support me.
- I will make sure that everyone understands what I am saying and ask staff to check that they have understood as I sometimes talk very fast and run out of breath.
- I will make sure that staff supporting me know what I can decide for myself and when I may need support to make decisions to keep me safe and well.

Action Plan

What's to be done	By Who?	By When?
Work with My Way facilitator to create person centred plan so everyone knows how I want to plan my future and what I want to change and help me achieve this.	Me and Margaret	December 2008
House mate matching – who do I want to live with.	Me, social worker and Margaret	December 2008
Social gatherings to meet new friends and increase my circle of support	My Way	Ongoing
Have a Planning Live meeting with Kirstie to find out all about me ,what I want to achieve in next 12 months and what my ideal weekly plan would be. February 2009.	Me, my family, social worker, Kirstie and her circle of support and Margaret.	February 2009
Find a house	Me, Kirstie, circles of support and Margaret.	May 2009
Find a PA I want to support me and who can help me do everything I want to.	Me, Kirstie, circles of support and Margaret.	May 2009
Find a support provider who wants to work with me in a different way.	Me, Kirstie, circles of support and Margaret.	May 2009
What's to be done	By Who?	By When?
Apply for funding to support my needs	Social Worker and Margaret	June 2009
Sign tenancy agreement	Me and my landlord	June 2009
Plan my week to make sure I am doing everything I want to and have enough money to do so.	Me and Margaret	July 2009
Apply for volunteer work with V Project	Me, Margaret and DCIL	July 2009
Apply for college	Me, Margaret, Connexions worker.	May 2009
Apply for benefits	Me, mum and Welfare Rights.	July 2009
Design the house as we want it to be.	Me, Kirstie and our provider organisation	July 2009
Organise a BBQ for everyone before we move in on 17th August!	Me, Kirstie, circles of support.	August 2009