

## READING ROOM

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Rose Davies- A  
parents perspective



Carmen's Story

## Stories

People have asked us to share more stories. We have put together a collection of short stories (from publications we have written or been involved in), and longer stories, often written by people themselves. You can also see video of people telling their stories on the pinboard section of our website.

### Linda

Linda had never had a job before and we weren't sure where to begin. So we decided to start with her interests. Well she loved rock and roll and hippies, coca cola and junk food, keeping her house orderly and riding in cars. We went through the interests one by one and tried to think of jobs. We had a little trouble thinking of jobs that revolved around hippies, rock and roll music and junk food. So we pursued the themes of neatness and riding in vehicles.

We decided to focus on vehicles because she truly loved motion.

Someone thought of the idea of pizza delivery. We all were elated. Of course that would work, she loves pizza. So, a member of Linda's circle went on the task and soon developed a pizza delivery job. On the first day of the job we realised very quickly that this was not the ideal job for Linda...she likes pizza too much - there was very little left by the time they got to their destination!

So back to the drawing board. Two months later, we met again.

This time we again went back to the riding in vehicles theme. We were about to give up when somebody in the circle suggested a courier service. She could deliver documents back and forth. A few days later one of the members of the circle developed a job with a small organisation with satellite offices. We tried it out and it was quite successful. Linda still has the job a year and a half later and still enjoys it.

### Joyce

Two years ago Joyce moved from the hostel where she was living to a semi-detached house in the city with Ruth. In the last two years she has had three different key workers supported by three different managers.

As a result, little was remembered about Joyce's views, what is important to her, or what life had been like in the past. She did not complain, she just thought that was how services worked.

Joyce's latest key worker, June, and the planning facilitator, Karen, met to talk about the planning process. Joyce wanted to collect the information about her life herself with some help from her brother and Karen. Over the next two months Joyce and Karen spent an afternoon each week around the kitchen working on a personal profile. When they had finished, Joyce

shared it with her brother to see if there was anything that he wanted to add.

Then they discussed where and when Joyce wanted the meeting to take place and who would be invited. Joyce decided that she wanted her physiotherapist to send a report before the meeting, but not actually come. Karen and Joyce talked about how she wanted the information from the profile shared with the others.

Joyce did not want to talk about her past very much although she wanted the group to have some information about it. They decided to transfer the information from the profile onto posters.

As agreed, Joyce introduced everyone at the beginning of the meeting, and then Karen read through the posters and asked Joyce to add anything she wanted to at the end. Then Joyce gave people coffee and some cakes that she had baked.

Joyce was asked what she wanted to change. On her relationship map there were two people that Joyce did not see anymore and that the staff did not know about. The first was Lucy, who used to work at the hostel, and had met up with Joyce a couple of times in her new house. The second was Peter, whom Joyce had met at a self-advocacy group. They had had a few meals together and had been to the cinema, but had not seen each other for 18 months. Joyce wanted to meet up with them both again.

Joyce also wanted a telephone and answering machine in her bedroom, a doorbell that worked, a hanging basket in the back garden and a carriage clock similar to her mother's. Joyce wanted to try new activities and visit new places.

The group worked with Joyce to turn each of these into actions. Her brother agreed to help her buy the carriage clock and bought her answering machine for her birthday. June and Joyce planned how to contact Lucy and Peter again. Eve wanted to go along with Joyce to try new activities.

Joyce said: 'I liked doing the booklet - it brought back memories. I liked looking at the things that I wanted to do and putting down my dreams - I didn't think that I could have my dreams. It was a very good meeting, better than meetings before - it didn't have people coming in and out like at other meetings. I could say what I wanted and I enjoyed being in charge.'

A year later, life looks quite different for Joyce. She met up with Lucy again, and the two of them regularly go out for meals together. Without any staff support they also achieved one of Joyce's dreams – seeing Buckingham Palace and going to a London show. In the summer, they went with another of Lucy's friends, Rachel, on a boating holiday. Lucy now also acts as an advocate for Joyce whenever she requires help speaking up.



Eve and Joyce tried many new leisure activities together, including the local bingo hall (they are now regulars), a jacuzzi and even canoeing. The biggest change is with Pete. They have been seeing each other for the past eight months and have just announced their engagement. Joyce is busy preparing for her wedding and her move to a new home with him.



## Stella

Stella is an attractive friendly woman in her mid-thirties. When we first began planning with her she was desperate to move out of the hospital where she lived. She said clearly that she wanted to move into her own house in the town near the hospital. She wanted to live near Jean, one of the nurses from the hospital, and Jean's mother. She was clear that she needed live in staff although this was more for reassurance than for any help with physical tasks.

A year after the planning Stella lives in her own house with staff to whom she has grown close but now she is ready to move on. Her greatest need is to live with people who care about her and whom she can love. She has lost touch with the nurse she used to know and has decided that although she likes the staff she lives with, she would rather live with a family. The agency which supports her is looking into the options.

For Stella, moving out of the hospital was the first step. Once she knew what life was like on the outside she could make a more informed judgement on what she wanted.



## David

Two years ago life was confused, busy and somewhat scary for David. From one day to the next, he didn't know where he would be, whether he would be locked in a ward or at home where rooms were off limits.

David's early years involved moving between special schools until he ended up at a residential school for children with autism. By the time he reached his thirteenth birthday he was living in a large hospital having been excluded from the special school system. After a few years living in a locked ward he was back with his family for short periods during the week and receiving a complicated cocktail of community and institutional services.

During the week he would spend one night in hospital and one at a respite hostel where there were two staff on duty just for him. At the weekends support staff would come and work from the family home.

During this time David had built up a reputation. Words used to describe David were - 'difficult to spend time with, destructive, without speech, aggressive, likely to hit out, a fast runner, autistic, hyperactive, a drain on the family, tiring to be with, an unknown quantity, mischievous, needs two staff with him when out, needs one to one when in'.

David had a positive reputation too but this was rarely talked about. All in all very little was known about what David really needed or wanted. We put together an essential lifestyle plan with David and the people who knew him well, including his parents, his sister, key workers and hospital staff. Although it was difficult for David to be involved, a series of small meetings and interviews took place. Through the telling of stories and the sharing of good and bad experiences a picture emerged and was shared with those involved.

The plan resulted in less concentration on reputation, rigidity, and structure and more attention being paid to David's need for happiness and enjoyment in his life. David eventually moved into a flat near to his parents' house and is now supported by four part time workers whilst retaining his place at the adult training centre for the time being. The people that support him have paid a lot of attention to helping David relax and feel safe and significantly less attention to trying to sort his 'behaviours'.

To begin with the team tried introducing David to new people and broadening his choices. This did not work and David was still showing through his behaviour that he was not happy. So the team changed their approach.

Instead of trying to help David learn new skills, they worked to help him to feel safe and control the few things we knew were important to him. Listening to him and going at his pace resulted in a real improvement in David's life.



Thinking differently about David's autism also had a significant effect on the success of the new support arrangement. Instead of thinking about structuring his time, the team and others thought about structuring their responses to his feelings of anxiety and confusion.

The first accommodation found for David, close to his parents' home and enabling easy access, unfortunately proved unsuitable and had to be changed. This was possible because the supports and services arranged for him were independent of the accommodation, so moving was no more difficult than it would be for anyone else.

David's reputation has changed as the way he spends his time has changed. He no longer stays awake for 30 hours at a stretch but sleeps well most nights for 6 to 8 hours or more. He takes no drugs to affect his behaviour. He sees people that are important to him on his terms and he usually controls when this happens. He gets to eat the food he likes and to spend lots of time moving freely about his flat instead of being limited to specific areas or locked in.

Instead of being bare of pictures, ornaments and curtains, David's living space is decorated with pictures and ornaments he has chosen.

When he wants to run or walk he can indicate this by getting his boots or running shoes and taking them to staff. David didn't learn these things because he was taught by his workers, he just did them himself, perhaps because he experienced for the first time a lifestyle that truly suits him.



## Paul

Paul has been referred to professional clinical services many times over the years. The referral forms list two areas for intervention - his hips and his behaviour. Paul has a degenerative hip condition and needs to 'weightbear' on his hip. His challenging behaviour was swearing and shouting when he was dissatisfied.

He did not want a physiotherapist to come anywhere near him and the psychologist knew that the issues for Paul were his environment and circumstances, neither of which was about to change.

The people who helped Paul to plan worked with him to find an alternative to the day centre: somewhere he could meet people and do something that mattered to him. He began a work experience placement for two half days a week, at the head office of a local organisation, supported by his community nurse.

Three years on, Paul is a paid, part-time member of staff. He has an important role and a network of friends and colleagues. He is supported by a local supported employment agency. Paul is no longer referred to clinical services. His 'physiotherapy' is standing at the franking machine and he has never been upset or angry at work.



## Janie

Janie is 25 and lives in a house with four other people. Her dad, her brother and lots of people who describe her as a friend - including people she lived with in the past - were included in her plan. Janie is described as someone who has profound multiple disabilities, and also as someone who is lively, fun and pretty.

Janie sleeps when she is bored and, as she sleeps a fair amount of time in the Day Centre, we guessed that this is something that doesn't make a lot of sense in her life. It will cost more for Janie to have her own personal day support, so this is something that has to be negotiated with the purchasers of her service and may take time. However, Janie also wants some ordinary things to happen more regularly.

We think that she would like her coffee in bed every morning and a cooked breakfast in bed on Saturdays. She'd like to go to concerts more and watch men in shorts play football. We think that she may like a cat.

Janie would like her support staff to make sure her socks aren't wrinkled when they help her to dress, and she doesn't want to use her wheelchair at all at home - she'd prefer an ordinary chair in the kitchen so she can be around when the cooking is taking place.

All of these things are our best guess, yet although she doesn't use words, Janie has at least fourteen different ways of telling us if our best guess is near to the right guess.



## Danny

Gill was asked to facilitate Danny's plan. She talked with Danny and his staff about how the planning could take place at Danny's pace, at Danny's time and at a place where he felt in control. To achieve this his planning meetings were staggered over a number of weeks. It was essential to Danny that he spend each evening between 4pm and 6pm in his bedroom alone with his tapes and microphone. He offered to share this time with the people helping him plan on Tuesday evenings in his bedroom.

The first meeting began at 4.05pm on the first Tuesday with people

sitting on the floor working on his plan. The meeting finished at 4.35pm when Danny said 'Go now!'. It took four Tuesdays to finish Danny's plan, but it was with him in control of how, when, where and for how long it happened.



## Alan

Alan wanted to move. In that service, care management usually meant filling in a form and then fitting people into a vacancy. The manager thought Alan should have time to decide what he wanted and discuss that with the care manager so they could come up with solutions between them. He asked Jean to help Alan.

Alan and Jean decided that they would collect the information suggested for a Personal Futures Plan. Alan had spent most of his sixty five years in a long stay hospital. There was a club there and he used to help out on a Friday night, putting the records on. He was never allowed to be the DJ and introduce records, and always wanted to do that.

Alan wanted to record the 'history' part of his Personal Futures Plan on a tape, as if he was a DJ. They did this together, and Alan began his planning meeting by playing it to everyone. During the breaks for coffee and cakes at his meeting, he played some of his other favourite music, such as Max Bygraves.

The meeting was relaxed and focused on Alan. He set the tone, asked Jean to read through the posters they had prepared and then he commented on them. Alan described where he would like to live and what he would like to do. Although the care manager still had the required forms to fill in, Alan had set the agenda, described his life and stated what he wanted in his way.



## Jo

When I did my own PATH the graphic facilitators asked me to think of images for my dream. I was stuck - I couldn't think of any images which represented what I wanted for my future. All I could come up with was a William Blake poem that I had learned as a child:

*"To see a World in a Grain of Sand  
And a Heaven in A  
Wild Flower Hold Infinity in the Palm of your Hand  
And Eternity in an Hour".*

That was my dream and I discovered that it was full of metaphors which meant a lot to me and which the graphic facilitator drew up on my PATH. The graphic facilitator came much closer to who I am and what I dream of by creating images than I ever did with all my explanations.



## Luke

Luke grew up on the outskirts of a large Scottish town. He comes from a loving and supportive family and lived with his parents up until the age of 21. His diagnosis of cerebral palsy meant that he attended one special school after another ending up in a day centre.

At home Luke spent his days watching TV or sitting by the half glazed front door looking at what was going on outside. Sometimes he went for respite to the local hostel for people with learning difficulties.

By the time he was 21 Luke's parents were finding it more and more difficult to care for him at home. They had problems lifting him, which meant that he very rarely got to go out except to the day centre.

Luke's mother approached a small voluntary organisation that was setting up a new group home. There was one place left but by this time it had become clear that Luke could not be accommodated there without extra funding for more staff time. This was applied for but refused.

While waiting for the funding decision members of the team got to know Luke and his family quite well. It was clear to everyone who knew them that Luke needed to move on. They began a person centred planning process with Luke, his family and a very committed keyworker at his day centre. The aim of this was to find an alternative to the traditional services which up until then had been unable to offer him a place.

The themes that came out of the planning were:

- ① Luke would like to live in his own place
- ① Luke must live in the heart of the city near to venues for country and folk music
- ① Luke would like to live with someone who had similar interests to him and who must find communication easy
- ① Luke would choose the person who would live with him
- ① Luke must keep up close and regular contact with his family
- ① Luke would like to attend sport events - football, horse racing
- ① Luke would benefit from having dedicated staff who could get to know him really well and provide consistent support
- ① Luke would like to be involved in choosing his own team
- ① Luke would like support to try out new things and develop more interests

People were then able to complete a service design to meet these

requirements. Central to the plan was the idea of a 'flatmate' – someone who would be especially recruited to share the flat with Luke. This would be someone who shared similar interests with Luke, who found



communication easy and was happy to share part of his social life with him.

When Luke first moved into his new flat he found life difficult. The change was incredible. He no longer saw his parents every day although they visited him often; he was supported by a team of people he hardly knew; he lived in the centre of the city having been used to the suburbs.

For someone who had spent most of his time either at home or in the day centre the new found freedom was quite daunting. Staff sometimes became frustrated because at first Luke showed no desire to do any of the things twenty-one year olds do, like going to pubs, going to films, going out clubbing. Instead he wanted to watch the cars driving past. Gradually they all began to adjust.

Staff started working at Luke's pace and Luke became happier to try out new things. A year after moving into his own flat, Luke took part in some further person centred planning. His life had moved on so the issues raised by the planning were different. Luke wanted to have his own transport and they talked a lot about exploring the options for electronic communication. Since then Luke has discovered a gift for drawing and he now attends a class at an ordinary college.



## Sabi

Sabi's family came from Pakistan when she was four. Sabi lives in a shared house and her family live a few miles away. Sabi's key worker, Kate supported her to develop a personal portfolio. It is difficult to know how much Sabi understands, but Kate talked with Sabi's family about different ways they could tell her story and make it as accessible to Sabi as possible.

They chose a dowry box, an important part of Sabi's culture and looked for things to put in it that Sabi could hold that related to her past and what is important to her now. They filled it with a tape of her sister talking about her childhood, a piece of her mother's sari, some joss sticks similar to those that her family uses. At the beginning of Sabi's PATH meeting, Kate and Sabi's sister opened the box and talked about what each item represented. This helped the team understand more about Sabi and her culture.



## Stan

Stan and Karen worked together for three months using the 'My Life, My Meeting' booklet to help Stan think about what was important in his life and what he wanted to change. Every week they spent about an hour together talking, taking photos, and describing memories.

One day Stan showed Karen three photo albums that no one else in the house knew about. He had decided that they were too important to show staff in case they got damaged but chose to include some photographs in the booklet.

When they had finished the booklet there were clear areas that Stan wanted to change and wanted to talk about with other people and also areas that he did not want to mention. Stan had had alcohol problems in the past and this was routinely brought up at every planning meeting.

Unlike most people who can 'lose' their past by moving jobs or moving areas if they wanted to, Stan's past misdemeanours were regularly paraded in front of him.

Through the process of thinking about what was important to him, and having time to do this at his own pace, Stan told Karen that he hated his job and they talked about ways that he could change this.

Stan and Karen used the booklet to prepare for Stan's planning meeting. Together they put the information from it that Stan wanted to share on posters. Stan chose who he wanted to come and arranged to have the meeting at his house. At the meeting he enjoyed choosing someone to read each section and then he talked about it and told people what he wanted to be different.

Together they agreed on what they could all do to change things.

Examples of goals from Stan's previous individual planning meeting were:

*"To have more independence' and 'to be self medicating."*

Now people are working to help Stan pursue his new found interest in taking photos, changing jobs and looking for opportunities to meet someone with whom he could have a lasting relationship.

The staff commented on how they learned things about Stan they didn't know even though some of them had worked with him for three years.



## Jo

Many people develop collections of video, photos, certificates, a family tree and other ways of recording their life. Jo describes how she has done this for Jacob and for herself:

'My son Jacob was born on June 13th 1996. The day after he was born a photographer came round the hospital and took a picture of him. He arrived home in time for the England/Scotland game in the European Cup. Friends came over to welcome him and we took lots more photos.

I've bought an album and one day soon I'll get round to sticking all the photos in it. In a box I've stored his name tags from the hospital, newspapers from the day he was born and video tape of the news and Coronation Street. At the moment I'm trying to work out how I can persuade Jacob to uncurl his toes for long enough for me to get a footprint. I am beginning Jacob's story for him.

When I started collecting things for Jacob I began to think about how I recorded my own life story. I have lots of photos and some letters I have kept from my childhood. When I have time and particularly when I go away on holiday I keep a diary. My education record and my work history is stored on my CV. Several times a year I meet up with some of my old college friends and we invariably end up talking about our student days. In all these ways I gain a sense of my own identity. I am reminded of who I am and what I have achieved as well as where I have failed. From looking at my past I can work out where I still have to go.'



## Philip

Philip was admitted to hospital thirty years ago with epilepsy. It was thought that his seizures had resulted in some brain damage. People thought this because it took him a long time to finish sentences - sometimes up to half an hour. He has difficulty finding words and has minor seizures while he talks. On a busy ward very few of the nurses ever had time to talk with him. They would try and finish his sentences for him leaving him very frustrated.

The hospital is now due to close and Carol was asked to make a plan with Philip about moving on. As soon as she met him she realised that he needed someone to spend time with him, getting to know him and just listening.

No one had done that for the last thirty years. As he spoke she wrote what he said down - he could read it back as he talked so that he did not forget what he was trying to say. Through listening to him Carol found out that Philip does not like living with people with learning difficulties and that when he moves out of the hospital he wants to live with someone who is not labelled. Knowing what he wants is the first step. Most other people are moving out of the hospital into group homes and Carol will have to fight to make sure that this does not happen to Philip.



## Lucy

Lucy's early years were spent in a succession of foster homes, group homes and 'respite' at hospital. She attended many different schools. As a young adult she moved into a small group home where she lived until difficulties resulted in her move to her own flat.

Lucy has a reputation, and at times is very troubled. Her new staff team were struggling to support her. She was often very angry with them and at herself. She was not easy to be around.

When we started to plan with Lucy we used Individual Service Design.

Sally, who knows her well and has a close relationship with her, told us about Lucy's early life. We wondered how it felt to be four and taken from your home. We thought about how a hospital smelt to a six year old and how big the nurses must have looked. We considered how it must have felt to want to live with your family and to know that they did not want to live with you.

Through doing this, support staff understood why Lucy sometimes tests their commitment to her and how important it is to her to feel loved. The key needs for Lucy were understood in this way:

- 🌀 Lucy has been rejected - she needs love and acceptance.
- 🌀 Lucy has been hurt - she needs to be safe.
- 🌀 Lucy has been frightened - she needs to be reassured.
- 🌀

Lucy greatly enjoyed the whole experience: she remarked about how many good things people had said about her and her self-esteem seemed to grow. She felt strongly that she wanted to talk more and record more about her life. She wanted to find her family coat of arms and decided to complete her own personal portfolio to help her to remember her past and share her plans and hopes for the future.



## Mary

Mary has never enjoyed living with other people with whom she cannot communicate. Two years ago, she began to talk about moving on. Mary's experience of planning is typical. She has had hundreds of assessments done to her throughout her life, none of which made any attempt to involve her in a meaningful way. She has some very clear ideas for the future and she has a strong group of people around her who get on well.

Mary is her own best advocate, continually campaigning to change arrangements which do not suit her. Mary and her support staff decided to invite in outside facilitators to help them plan for change, using PATH. An all day meeting was scheduled to which Mary invited her parents, her key worker from the day centre, members of the house team and her speech therapist.

A year later, Mary has achieved many of her goals. She goes out weekly to the same pub, she is learning to read and she has been on holiday to York. However in many ways it has been a frustrating year for Mary. She still lives in the same house, although plans are being made for her to move on. It has taken a year for the social work department to agree to fund a day worker so she can cut down her days at the Adult Training Centre to three a week. Mary has been to biology classes in an ordinary school but it is proving difficult to persuade a college to offer her a place in an integrated class.

The review meeting had a very different tone from the original PATH. The same outside facilitators were asked in and the same people attended the meeting. This time Mary took far more control of the process than she had the year before. She did not allow anyone else to speak on her behalf.

When people suggested that she needed to get out and meet more people she indicated that this is not a priority for her. She feels that she has enough people to talk to although sometimes they do not have enough time to talk to her. Her main priorities at the moment are her reading, her RE classes and moving into her own home.

Things had changed. The other people at the meeting were there to listen to what Mary wanted and to say what contribution they could make to supporting her to get it.

Mary now has a dedicated team including her parents and paid workers, many of whom also see themselves as her friends. Person centred planning has helped Mary become an assertive young woman who is both sure of what she wants and determined to get it.

However, she is still frustrated by the amount of time it takes for her to get anything and by how much still has to be achieved. She chose to have a plan because she was not satisfied with her quality of life. The planning was the start of a process of change which has not moved fast enough for her.



## Phyllis

For Phyllis's family this meant changing the way they helped to support her. Two years ago Phyllis left her parents' home and moved into a house with five other people. She never settled in her new home. She wasn't able to communicate with the other people who lived there and she was disturbed by the continual harassment from the kids who lived on the estate nearby.

The manager started a process of person centred planning with Phyllis and this led to changes in the relationship between her and her family. She had been used to going to her parents' house every weekend for the day. The whole family came over. For some time she had found this more of a chore than a pleasure but had worried about telling her parents in case they were offended. Once this was understood people agreed that Phyllis would go to her parents' house at times which suited both sides and that they would come and visit her in her new house.

The planning process also confirmed that Phyllis did want to move. She wanted her own flat in the same neighbourhood as the rest of her family. It was difficult to find a flat, and Phyllis' parents were ready to give up.

However Phyllis and her support team would not let the matter lie. A flat was found but the social work department refused to pay the full costs of her support. Her family and friends offered to provide support for six hours over the weekend and this allowed the 'package' to go ahead.



## Ernie

For Ernie and his family, support became a two way thing. Ernie is in his early fifties and moved out of hospital two years ago.

During his seven years in hospital his family acquired a 'difficult' reputation.

They complained constantly that the service did not meet his needs. To help Ernie plan for leaving hospital his social worker talked with his family about where he should live and how he should be supported. His parents, his sister and his two adult children were delighted that he was moving out of hospital. They wanted to see him more and to take an active role in caring for him. It was arranged that he would live near his family with support from a combination of paid carers and family members.

The last two years have been a traumatic time for the family. Ernie's Mum and his sister have both died. His father has dementia. Ernie has been there throughout, supporting them as they support him in a way that would not have been possible had he not been living among them.



## The Smith family

For the Smith family, person centred planning enabled them to stay together as a family and being trusted to take a lead role in arranging care and support.

Joan Smith has three sons - Charlie who is eighteen, Luke who is sixteen and Nigel who is fourteen. Charlie and Luke have a genetic disease that entails progressive physical and cognitive deterioration and results in an early death. Both of them are doing much better than doctors predicted and may even survive into their early thirties.

Joan separated from her husband several years ago and struggled to look after the boys with the assistance of the rest of her family. She has since remarried and Gary is a very supportive stepfather. Although social work has been involved in the case for a long time there has always been bad feeling between the dept. and the family.

Over the years the family acquired a bad reputation with services and were seen as unable to take care of the boys. One of the phases of the disease involves loud and difficult behaviour. Charlie went through this phase first and Luke began to enter it while his older brother was still going through it. The family lived in a two-bedroom house and Joan felt that she could cope no longer. Both boys were admitted into hospital and a long debate about their future began between the social work department and the family.

It was at this point that a service brokerage agency became involved. The service broker met up with the different members of the family to draw up a person centred plan. He gathered information from them about what worked well for the boys and what did not. In this way he made suggestions for the future based on the evidence of what had worked for the boys in the past.

The result was a proposal for buying large house with separate bedrooms for the boys and a big garden. Support would be brought in and control over this would be held by Joan and Gary. There was a shift from seeing the family as the problem to seeing them as capable of looking after the boys but in need of constructive support which was under their control. The necessary money would be given by the social work department to the service brokerage agency and managed jointly with the family.

Although there were problems in shifting the view of the professionals who had been involved with the family they gradually began to see the story from the family's point of view and to appreciate how badly they had failed them in the past.

The family have now moved into a bigger house and employ their own staff. These are also family members. The service brokerage agency continues to manage their money with them and help to plan for the future when the boys' support needs will increase.



## Graham

Graham is a man in his early forties who lives in a small village. He has lived there all his life with his dad. Every weekday morning he is picked up by the social work bus which takes him to a day centre in the local town. Graham knows everyone in the village. He goes to the local pub every Friday and shops in the post office almost every day. Recently his father was diagnosed as having terminal cancer.

It looked like Graham would have to leave the village and provision would have to be found for him elsewhere. Graham's social worker began looking at the options available in the local town.

At the day centre they knew that Graham would be devastated to lose both his father and his community at the same time. One of the support workers, Fergus, decided to see if anything else could be done. He travelled to the village one day and began knocking on doors. He explained to Graham's neighbours that he would have to move out into supported housing when his father died. Nobody wanted that to happen.

Graham and Fergus called a meeting to which about twenty people came. Between them they sorted out how they could support Graham to stay living in his own home when the time came.

Two months ago Graham's father died. Graham feels the loss deeply but he has insisted on remaining in the house when he has always lived. He still attends the day centre and someone from his support circle meets him off the bus everyday and goes home with him to cook a meal. No one thought he would manage to sleep on his own but he does.

There are fourteen people from the village in Graham's circle of support. Between them they are determined to ensure that he does not have to move away.



## Sylvia

Sylvia left Olive Mount Hospital in Liverpool over ten years ago. To help with the transition from long stay hospital to community life, she attended classes for people with learning disabilities for six years. There came a point when Sylvia decided that the time had come to leave college. In fact she was adamant :'I'm not going there anymore'. Since then, Sylvia has tried cookery classes, keep fit, craft groups and ordinary classes at the local college. Through all these activities she has become increasingly confident, making more of her own choices and decisions about her future.

One of the most significant ways in which she has become a part of her local community is through her local church. Sylvia started attending the morning service there over 6 years ago. Gradually, with the help and support of a number of members of the congregation and one of her staff, Sylvia started to help clean the church on Fridays. Before long Sylvia was a fully fledged member of the cleaning team, a local group of women affectionately known as the 'holy dusters', who have become her good friends.

Over the years Sylvia has taken on more responsibilities in the church. She has been elected to carry out official duties on Sundays, distributing hymn books and taking the collection. Sylvia also rings the church bell before the start of the service to call people to worship.

Everybody knows Sylvia. During the week she attends a social gathering at the church hall where people meet up for a chat and a cup of tea. Sylvia has become a respected and active member of her local community.



## Annie

Annie is supported by a small parent-led supported living agency. She has a lively personality, a wicked sense of humour, and a sharp memory. She does not use words to communicate, but people describe her as a great communicator who is straightforward and honest. Annie, her mother and the team manager decided to use Annie's Essential Lifestyle Plan as part of the recruitment process.

The organisation has an equal opportunities procedure which it also wanted to follow. An advert for staff for 'a young woman' was placed in the local paper. Over thirty people applied. The manager and Annie's mother short-listed these to seven who were then sent a copy of Annie's Essential Lifestyle Plan.

When they were interviewed, many of the questions focused on how they would implement and monitor the plan. The second part of the process involved Annie meeting the final applicants and them all having a meal together. Annie's mum says that Annie made it very clear who she felt positive about. Finally, three staff were chosen who had demonstrated that they understood the importance of fulfilling Annie's chosen lifestyle as described in her plan; who would provide the support she needs; and who were approved of by Annie.



## Heather

Heather used to work in the day centre as an Occupational Therapist.

Colin attended the special needs group, and the fact that he does not communicate with words did not prevent them developing a good friendship. After she left, Heather kept in touch with Colin and he came round to her house for meals, spending time with her and her partner Jim. When Jim was 30, Colin was invited to the party and met the rest of their family and friends.

Heather's sister Sheena left her job to go back to college part time.

Heather knew that Colin hated being at the day centre and had often talked to Colin and his Mum about possible ways that he could spend less time there. Heather wondered whether Sheena would be interested in them spending some time together, and talked to her about it. Although Sheena had met Colin four or five times, she had never spent time alone with him and although she had enjoyed being with him, she was nervous of providing the physical support that he needed.

Sheena and Colin decided to get to know each other better and for a few months they went out with Heather during the evenings or at the weekend. After a while, Sheena felt confident enough to spend time by herself with Colin, and they clearly enjoyed each other's company.

Colin goes to the day centre four days a week now, and he spends a day with Sheena exploring the city. Sheena says that she has tried activities with Colin that she had never thought of doing. They watched an ice hockey match last week, and went greyhound racing a few months ago.

There have been times that have been difficult or confusing for both of them. At a nightclub one evening, Colin was surprised to get Malibu and milk instead of Malibu and coke as Sheena had misheard his Mum describe his favourite tippie. Sheena was frustrated when they went riding as although she had been told by the day centre staff that Colin loved riding, that day he didn't want to go near a horse.

Heather, Colin, Sheena and Colin's Mum now meet regularly as a Circle of Support. They are working with a local supported living organisation to look at the possibility of Colin employing his own staff so that he can have his own place and spend all his days away from the day centre.



## Karen

Karen is now 37 and has lived in large group living situations, firstly in a long stay hospital and then a nursing home, since she was twelve. Her mum, dad and two brothers love her very much but were advised by professionals that it was better that she live away from them in an institution. They always kept in touch with her and visited her regularly. Karen has a learning disability, yet most of her support needs are around her mental health problems.

It seemed that although staff cared for her the nursing home was finding it increasingly difficult to support her well.

Finances were available to support Karen in her own home yet her Mum and Dad didn't want her to move away from the safety and care of the nursing home.

Karen experienced an acute phase of mental distress when she cried a great deal, made herself sick and destroyed her clothes. She could not tolerate any of her belongings being in her room. Karen was admitted to a small in-patient unit as an emergency. Her parents understood that she was in hospital and that she was ill.

Karen's mental health began to stabilise and staff at the unit began to understand her. A care manager began the planning process with Karen, her family, and staff at the in patient unit and at her former home to prepare for her discharge. There were some setbacks. Karen's medication needed to be finely tuned and sometimes changed. At one stage she was particularly distressed and had to be sectioned, yet people continued to learn about her and were committed to planning with her for life after her discharge.


Gradually her parents began to trust the care manager and clinical staff who were working with Karen and together they developed a detailed plan of how to support her when she is well and when she is ill. A specification was drawn up for her new service.

When it comes to monitoring Karen's contract, there are clear indicators of whether the support is being delivered in a way that makes the best sense for her.

For Karen, this means that for example:

- ⌚ She must be supported to see her parents and brother Robbie, every Saturday afternoon at their house
- ⌚ She must go out at least once each day to Sue's cafe, the Albertpub or the Toby Jug
- ⌚ She must always have enough clothes to be able to change whenever she feels dirty



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- ④ She must have her blood levels checked regularly
  - ④ The care manager does this in a number of ways, through talking to Karen and her staff and looking at documentation such as the activity log and the records of blood tests.

This sort of monitoring ensures that services are responding to people as individuals. Over time people change and the specifications need to change, through both 'fine tuning' and major adjustments, to reflect people's new priorities.

## Doreen

Doreen is married with two children, and works as a secretary for an engineering firm. She has been Donald's citizen advocate for 12 years. She was originally introduced to Donald through a citizen advocacy project when Donald was living in a locked ward in a long-stay hospital. He could not speak and had a label of 'profound learning disability and challenging behaviour'.

The project provided some initial training and made sure that Doreen and Donald were happy with the partnership. Since then they have become an important part of each other's life. Donald has spent weekends and holidays with Doreen, her family and friends. Doreen has assisted Donald at difficult times, like accompanying him to the general hospital for an operation and ensuring that staff who did not know him paid attention to his needs.

She helped him move to his own flat in the local community. Doreen has also helped Donald to become more confident and self-assured by showing that he matters.

Doreen keeps in touch with the citizen advocacy project to share ideas, get support and meet other citizen advocates but she does not 'report' to the project, and the project no longer has any direct role in her relationship with Donald.



## Doris

Doris is an employee of the Circles Network. She works 5 hours a week formally but is always around and about the office. She regularly facilitates workshops at conferences and gives talks at gatherings about her experience both of having a circle and of working in the field.

Doris' history is typical of many people who use services. At the age of 9 she was sent away to boarding school which she hated. She never returned home to live with her parents. When she was 18 she was sent to live in hospital on an all womens' locked ward. She did not leave hospital until she was 21 when she moved out into a hostel. They were still locked in. Throughout this time Doris worked first at the Wimpey bar then in a hotel and finally at the Zoo. Her work gave her little in terms of money but much in terms of friends and job satisfaction.

Eventually Doris moved out into a house sharing with someone also labelled as having a learning difficulty who she did not get on with. The other woman was violent towards and despite opposition from the agency which supported her she moved out into her own flat. At the same time she was attending a day centre at which she felt bored and isolated.

Things went from bad to worse in her own flat. Doris was almost completely unsupported. She was lonely and miserable. She wanted what she terms as a personal assistant - someone to keep her company and help her look after both herself and the flat. The home care team 'didn't want to know'. Throughout this gloomy time Doris continued to be involved with People First and attended her local church. One of her friends at People First, Kate, already had a circle so Doris knew what they were. She attended a Circles gathering and met Liz.

A short time later in August 1994 Doris broke her leg. 'It came to a crisis to get me a circle. Because I'd broken my antibia and fibia bones...I was in plaster for 14 weeks with a pin in my leg for two years and three months'. That was when the circle really got started. Doris called it a semi-circle at first because it just included her, Kate and Liz. At first they just visited her in hospital. Once she moved back home they helped her get out, supporting her on and off the bus and taking her to the pictures.

In the beginning the circle concentrated very much on widening Doris' social circle. Doris says that she immediately 'felt happier and more cheerful. I wanted to look respectable and tidy'. It was the knowledge that she was loved and wanted that made the difference to her life.

Very soon Doris was inviting more people to be part of her circle. Keith and Jan are friends Doris met through Kate, Joyce she knew through People First and Sue is Mandy's sister. 'They support me and we support them. It works both ways. Say if they were upset, we'd support them and when I broke my leg they supported me.



We work as a team, put it like that'. In the beginning the circle met regularly. Doris went on picnics, out shopping, out for meals and barbecues. She went to parties and stayed over at peoples' houses. She did all these things either with her circle or with people she met through her circle. They helped in practical ways as well assisting her to get a telephone which takes incoming calls.

Now Doris is busy with work the circle meets less regularly. However at the moment they are helping her decorate her flat. 'Keith's going to do the ceiling where I can't reach. I'll do the bottom ledge, bits I can get to.

My social worker's offered to help. Jan will probably do the wall. Liz sandpapered the wood part on the wall'. Doris has chosen the colour scheme. Many of Doris' dreams have been fulfilled. She has many friends now and a job in which she is both needed and rewarded. She is also a member of someone else's circle. Her vision is extending. She wants to travel more, to have a computer and to ride a bike and it is important to her that her circle continues to meet. 'They help me get what I want, what I need, when I need it.'

