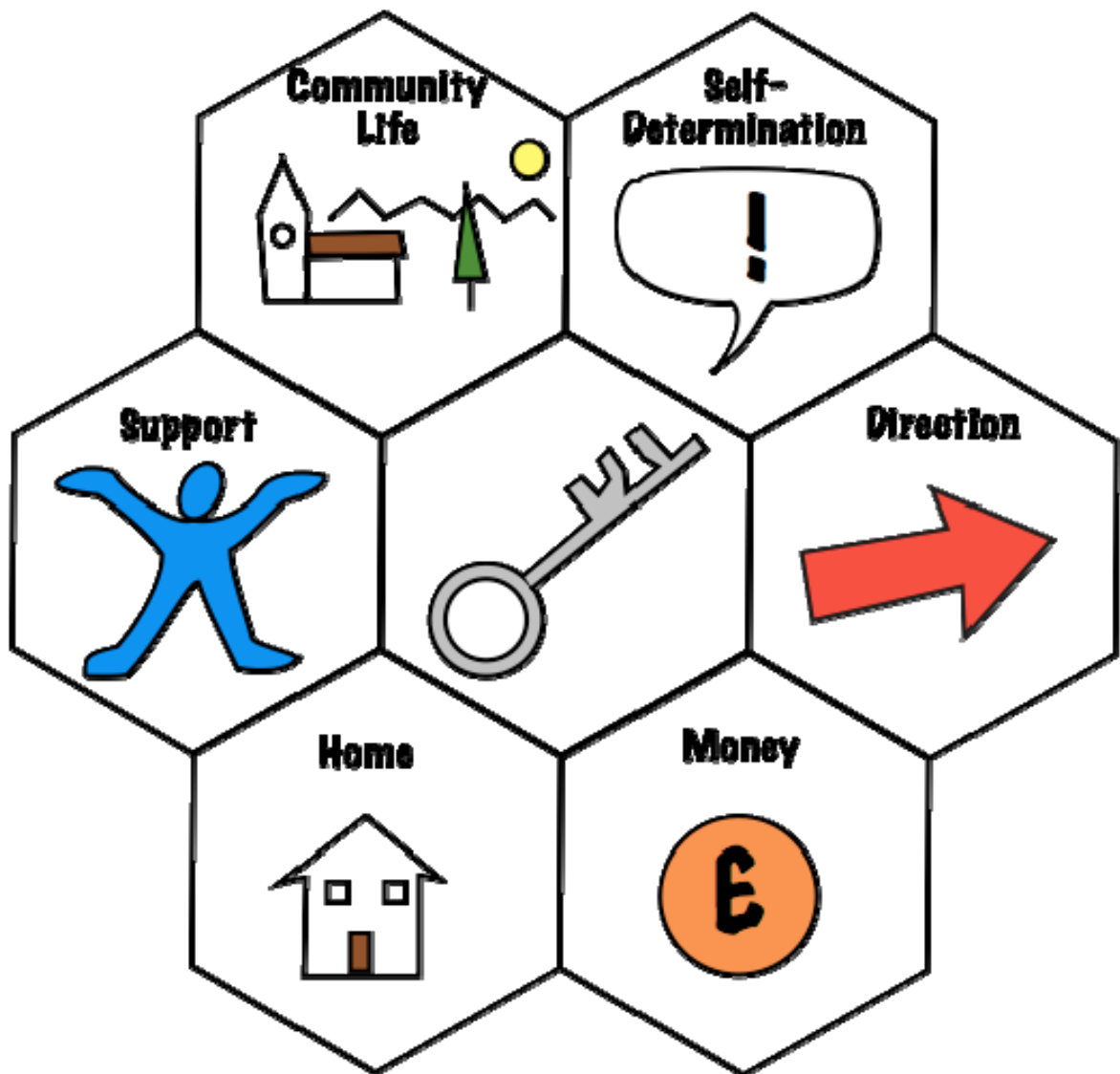


Self Directed Support

People's stories

Volume two



Dated 11 /01/ 2007 to 22/0 6/2007

Individual Budgets is a National programme to change the organisation of social care in England so that people who need support can take more control over their own lives and fulfil their role as citizens.

The logic is, if the support a person receives fits them better, it will improve their lives and the communities in which they live.

Part of the role of the Self Directed Support team is to capture some of the experiences of people who are directing their own support.

In doing so, this will help everyone to learn more about the programme and ultimately make people's lives better.

Hearing or reading about the lives of individual people is a good idea because:

- Stories are a very powerful and direct way of telling everyone what a person's life is really like.
- It is easier to remember stories about individual people rather than plans, policies and service systems.
- We can generate lots of learning to help us improve the way we do things
- You can sense the real creativity that individuals can bring with just a bit of good information.

The stories that you will read are just a few examples of how people have been taking control in Barnsley.

Thank you to the people who gave us the permissions to share their stories.

Mrs D's story

Mrs. D used to have support from carers organised by social services, but changed this to have an individual budget instead. Mrs. D uses this budget to pay her own personal assistant who she employs with help from her daughter.

She says that “the carers sometimes used to come at an earlier time when they were filling in for the usual carers, and sometimes they would have to wake me up and I would have to hurry to get downstairs, this made me quite anxious when I had different carers visiting. I also got on better with some carers more than others. Now I have my own personal assistant and she's ever so good. She will do anything I need, from helping me take my medication to cooking meals and supporting me to the hairdressers. I used to get two shorter visits from carers every day, but I've changed it to one longer visit from my personal assistant, which means she has time to stop and chat, and this suits me. I don't feel safe being outside by myself, but when my personal assistant is here, we can sit out in the front garden and I get to see my

socialising”.

Mrs. D is supported in using her individual budget by her daughter, who agrees it is working well: “It's taken a lot off me; I used to have to sort out my mum's medication because the agency workers can't give medication and there were other things they were not allowed to do. But mum's personal assistant is excellent, and it's less rigid than the service mum had before. This way, you can pick your own times, and my mum is happier independently arranging appropriate times for the personal assistant to visit.

Mum was quite apprehensive to begin with, but it's working well. There were a few problems with paperwork at the beginning, and the first payment from social services didn't arrive on time, but we're ok now. There are still things I need to do, like send timesheets to a payroll service to be processed, and keeping records of how mum has used the money. Some people, like mum, will need someone to help them to keep on top of

neighbours, so it helps with Mrs. D is also using some of her individual budget to pay people she knows to give her lifts to see some of her relatives (“we tried taxis, but they don’t always come to the door, to escort me to the vehicle), and to pay someone to keep her garden in order. She says “I’m looking forward to sitting in my garden in the summer and seeing people I know”.

this”.

Mrs A’s story

I am a 91 year old lady. I am very independent and very intellectual. I worked fulltime as a lecturer till I retired , now I work as a volunteer lecturing mature students twice a week at Huddersfield university once in literature and once in psychology . I use to pay privately for my carers and social services was not involved, then my health took a downward slide after having a series of falls and I started to need more extensive care.

A social worker came to see me and mentioned Direct Payments and asked if I was interested, I said I was so she arranged for someone from the Direct

I pay for these carers privately and my accountant does the payroll for them. I employ an agency with my direct payment monies they come in twice a day once at tea time to give me something to eat and assist with personal care and again in the evening to assist me to bed. I am not happy with the agency they appear to be under stress sometimes not turning up the direct payment support service are going to support me to find an alternative agency. The agency is very important as my live in carer works 8.30am to 2.30pm with a day off during the week and is on call every night.

Payment support service to come and talk to me and my carer as I am a little hard of hearing so prefer my carer to be there in case I mishear something and then she can explain to me later.

I decided it all sounded like a good idea so I went ahead to get it organised so I could get on with my busy life.

I employed 2 carers 1 live in carer and another carer to drive for me and to do my admin the hours per week vary depending on my schedule.

Before I started having a direct payment I went into a residential home to have some rehabilitation “I felt like a fish out of water intellectually it was not suitable my health started to get really poor and I felt sad and lonely”

In 2006 I got the Queens award for voluntary work I have done at Huddersfield University.

Because of the direct payment and the care I purchase privately I “FEEL ALIVE” and look forward to the future.

The direct payment support service, are very good and support me with the financial monitoring of the direct payment.

Having a direct payment and purchasing my own care as really made a difference to my life it has enabled me to keep my independence still teach my classes and remain in my own home. I would describe it has a “LIFELINE”.

J's story

J is a 19 year old man who has autism and a severe learning disability, J has no speech but communicates to others by using signs, the signs are familiar to his family but not to others.

J's interests include holidays, car washes and funfairs. He enjoys spending a large amount of time on his playstation, he used to spend hours alone on it but now prefers to have company of others to help him. J is a very anxious young man, he particularly gets anxious about going to new places. J attended a specialist school which supports individuals with autism, even when J was at school his parents often worried that due to J's behaviour towards others, services would say that they could no longer support J.

Before J left school his social worker tried to find a place for him in a day service, but places were very limited and J required a lot of support. Initially the family looked at a placement in a day centre, they patiently waited for the report to come back, they waited.... and waited.... and waited.....after 12 months the report arrived

only one month before he left school and it was too late for the placement.

The family looked at another day centre after an assessment the centre felt that it would be an inappropriate placement.... So what about J

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Frantically the family looked for other placements but there were none appropriate for him. Clutching at straws they contacted social services and J's social worker got a re-assessment for the centre that had turned J down. He was accepted and started at the centre in January 2006. Over time J's behaviour deteriorated, this meant that J was unable to go out with others attending the day centre because of how he responded to others. At the day centre the incidents became more regular sometimes on a daily basis, obviously J was not happy and he was letting others know the only way he was able. His parents dropped him off at the centre daily, but by the time they got home they, they just wanted to turn around and fetch him back they could see he wasn't happy, but at the moment this was the only

Unfortunately for J it was now very frustrating for J's parents sat at home wondering if this was the day that services said they could no longer support J. The family felt that at times people supporting J at the centre had not given honest feedback about what J had been doing.

When J was 17/18 he received a direct payment to be supported by carers after school 10-20hrs per week x2 carers. His mum called this "a baby sitting service".

J's parents went on holiday and J's carers supported him at home. On returning from the holiday J's parents felt relieved when the carers told them that they had coped with J fine. After this J's parents decided to withdraw J from the day centre. J's parents had thought through some of the options open to them???? They could re-mortgage their home???, they could get rehoused???

Social workers told the family that they could use a direct payment to provide a care package at home. Initially the family just looked at this as an idea and not a reality for them. They were aware that the cost of services supporting J was £30.00 per hour.

option open to them. They dreamed about how they could put the money to better use for J. "With that money we could give J a better quality of life".

Eventually the family just ran out of options, there were no day centres left to tap into and they didn't want J to go into residential care. J's social worker talked again about a package of care at home.

J's Family decided to take the big step when a business solution was suggested which would be built in the back garden. J's dad is more optimistic about this than all the other options they have tried." It was something that we had thought about for later in life" says J's Mum. Sometimes J requires x3 carers at any one time. This means that the family home can be very crowded at times.

The family have employed all three of J's carers. They all bring different qualities when supporting J. But the family know that they all care about him they are all spending time getting to know J.

The new build will be ready in the next month, it will be kitted out with toilet, sink, and a

People giving the support don't swap and change. He goes out and does lots of things, his parents still like to know where he's gone but that is just to help J's carers know what J likes and doesn't like in different places. J has a mobility car which the carers have full access to for taking J out and about. You can see the contentment in J now, he is not so demanding on us. Not too long back he never gave us a moment.

J's mum said "he's very sensitive our J, a lot of people didn't understand him, one of J's carers have suggested working on a life book for J so that important information can be passed on to others. "It would have been far easier to put J in a residential place but we didn't want that for him".

J's dad said "because there weren't any options we've ended up with something better than we could have wished for".

kitchen area, a cosy seating area, computer and printer and table and chairs. It's a comfortable warm base for J and his carers to spend their time in between their travels. So what's it like for J now..... Well J very rarely shows that he is unhappy, his parents feel this is because he has got the support he needs, and the What difference has it meant to J's parents, well they now have more time to spend with each other. They are happy because they know that J is contented and quite chilled. Now the time they spend with J is quality time as they are no longer rushing around, "now that the pressure is off us we are more refreshed for him". It really is having a positive impact on him.

J also gets respite care support from his carers.

What will J be doing in 6 months..... he'll be going swimming once a week, and he'll have a little job at the horse riding stables, mucking out and doing odd jobs. Watch this space.

Mr G's story

At the moment I get ILF funding and part direct payment and part day services funding, I have had a service for over 10 years since my mum became ill.

It was my social worker that mentioned individual budgets to me, the social worker left us some leaflets to read, after reading them and discussing it with my mum I decided to give it a go it sounded as if it would suit me down to the ground I decided it would give me more scope, widen my experiences and be more flexible because the hours I get at present do not meet my needs.

My mum has always encouraged me to take chances and make mistakes; I am able to budget my own monies. I decided to go ahead with an individual budget. My social worker assisted me to fill out the self assessment questionnaire; after the questionnaire was filled in it took about 3 weeks then my social worker came and told me what my budget was then gave me information on the help I could get to do a support plan . I decided to have the help of a support broker; my social worker contacted him for me.

When my support broker visited he was chatty, down to earth, he was easy to understand and used no technical jargon , in fact I think my broker is the “cats whiskers” he went at my pace and did not rush me, it was a easy process and very enjoyable.

My ILF is used to purchase services from an agency I don't employ my own personal assistants. After I had checked the draft plan Chris my support broker typed up the plan for me when it was finished it was sent to my social worker for approval, the social worker contacted my broker who contacted me to say some things needed to be added in to the plan, this as been done and sent back to my social worker but I am still awaiting a decision if the plan has been signed off or not, my broker was very efficient but there has been delays from the local authority.

I really enjoyed it when I visited the broker at his office to type up the support plan. I am going to use my individual budget as follows.

ILF monies will pay for care and the other monies to go to digital camera classes, carriage riding, creative writing, art, and to expand my social life and try out new experiences. I would say to anyone thinking of an individual budget “go for it, its easier than you think, but get the right broker this is essential as it makes the process easier, it becomes a mini friendship” this is my mums thoughts I would have preferred it if the broker had not been based in local authority offices, but think been employed by the local authority is a good idea.

I think brokers need to be experienced and worry that if brokers come from the voluntary sector they may not have the necessary experience, the broker my son had was experienced and made the whole process pleasant I cannot imagine managing without the help of a support broker. I am 35 years old; I have a physical disability and use a wheelchair fulltime so having an experienced broker who I trusted was essential.

Mrs B's story

This story is told by Mrs B's daughter as Mrs B's verbal communication is very limited, but mum agreed to everything that was said.

My mum already had a care package provided by an agency, my mum is 74 years old, fulltime wheelchair user who has had a severe stroke, she has a traditional care package, but was not happy as the agency sent 24 carers in 21 days, this is when the social worker told us

Mum is using her individual budget to purchase care from an agency she can purchase 1 hour more a week with an individual budget than she could with traditional services, it has not made much difference. Mum does not like respite but has agreed to have 1 week every 3 months to give her husband a break, this respite is paid for by the Primary Care Trust because she has nursing needs so this does not affect the individual

about individual budgets then Wendy came and visited and explained the process, mum decided to give it a go because it appeared to be more flexible and we would have more control.

Mum had help to do a support plan from a support broker; he gave us a lot of information and helped us in other areas as well he certainly knew his stuff.

The broker e- mailed us a support plan template and we did the collating of information ourselves it did not take to many hours it was just difficult finding the time to do it, the broker collected all the information from us and typed up the support plan for us we were happy with the end result.

budget.

The social worker has been very slow the plan has been approved but there is still no start date we have been waiting for the social worker to contact us but he hasn't so we will chase him up this week.

This is what my daughter thinks

I think you have more control with an individual budget I think the agency will provide a better service as mum calls the shots and if she's not happy can change agency.

My Husband says he is happy with me having an individual budget as long as I am happy.

Over the coming months the Self Directed Support team will be working with people who are in receipt of Direct Payments to enable them to have even more choice and control through Individual Budgets.

Sharing people's stories will be an essential part of this journey.

For more information about Self Directed Support you can visit:

www.individualbudgets.csip.org.uk

www.in-control.org.uk

in addition a new network has been established to support local partners to further develop self directed support, visit

www.sdsnetwork.org for further information

For more information, contact the Self – Directed Support Team on 01226 772425