

## **Self Directed Support & Families**

Spring 2008

**Valuing People**  
Support Team

*This newsletter is about some of the important things families of people with a learning disability need to know to have more choice and control in their lives.*

Welcome to another Valuing People Support Team newsletter which has a focus on families and 'self directed support', or what has been more recently called Personalisation.

The aim of this newsletter is to try and give families some information about personalisation and the different ways that it can help people have more choice and control in their lives. We are going to do this through stories from families who are already 'doing' self directed support. We asked the families to tell us:

- What made you try self directed support?
- How has it changed your family's life?
- Have you had to overcome challenges along the way and how?
- Do you have any top tips for other families?

We know that whilst self directed support has led to wonderful changes in some families' lives, other families are worried about how it works and if there will be more pressure and responsibility on family carers. To others, this newsletter may be the first time they've heard of self directed support. This newsletter is not going to explain everything in huge detail, but it should give you a good understanding of what it means and signpost you to more detailed information.

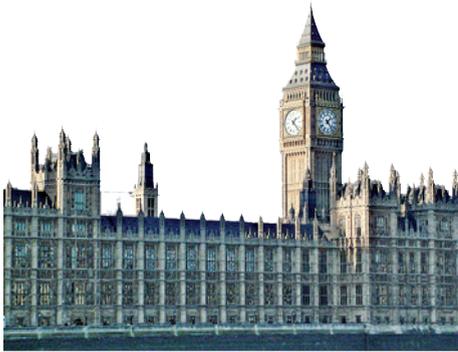
I hope this newsletter will help families understand more about self directed support, how it can improve the lives and opportunities of people with learning disabilities, and that families can have choices and control in their lives without having to do everything themselves.



*Cally Ward*

**Valuing People Support Team**

### Self Directed Support, Families & Policy



Personalisation is now a mainstay of government policy. It is also one of the top five priorities in Valuing People Now. The idea of personal budgets is not new. The In Control pilot programme ran very successfully between 2003 -2005 across six local authorities. Two-thirds of local authorities are now involved in the second phase. You can see the evaluation

of In Control on their website. Government ministers were so taken with the concept that they launched their own individual budgets programme in 13 local authorities.

In December 2007 the Government published ***Putting People First: A shared vision and commitment to the transformation of Adult Social Care***. This says how the Government are going to try and make social care more personalised, giving people more choice and control. Following an assessment, personal budgets are to be given to every individual eligible for a social care service. Whilst this may be in cash in the form of a Direct Payment, it can also be held by councils or providers to be spent on a support package chosen by the individual.

The key issue is that local authorities will have to be very clear with people how much money is going to be allocated for their support in a way that does not always happen now. So, you do not have to have a Direct Payment if you do not want one.

Over the next three years Local Authorities will be getting **A Social Care Reform Grant** to help make the changes happen. The total grant is £520 million over three years which works out at about £3.5 million for each Authority.

Some families are telling us they are worried. Some think Personalisation might be away of local authorities cutting services to people, or giving families more responsibility. It will be very important to make sure this does not happen.



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Money is a big issue and lots of people are currently talking about how social care is to be funded in the future. The Government is going to bring out a Green paper later this year and we will all have an opportunity to respond to it

The key issue for us all is whether the personalisation of social care is going to provide us with an opportunity to develop the sorts of supports that families having been demanding for many years. Families tell us time and time again that the stress in their lives is not caused by their family member with a learning disability but the difficulties of getting the right support from services. Families have been demanding more choice and control for years; self directed support has the potential to deliver it.



### How is the Government going to support this to happen?

#### Nationally

As part of CSIP's (Care Services Improvement Partnership) Social Care Programme there is now a **Personalisation Team** headed by Martin Routledge and Zoe Porter. For more information, see the websites: [www.individualbudgets.csip.org.uk](http://www.individualbudgets.csip.org.uk) or [www.personalisation.org.uk](http://www.personalisation.org.uk)

Or contact the Administrator, Sheila Stirling on 0161 237 2952.

#### Regionally

Each region has a person who is leading the work on self directed support / individual budgets. To find out what is happening in your region or to contact your regional lead, please check the CSIP website at [www.csip.org.uk](http://www.csip.org.uk)

#### Locally

Each Local Authority will use their portion of the Social Care Reform Grant to help personalisation happen in their area and each area should also have someone who is taking a lead on this. You may want to find out who they are so you can ask what's happening in your local area.

### Understanding the Jargon!



Families have told us that it feels like there's a whole new language around when trying to get good support. Below are some of the main words and phrases most commonly being used and some quick definitions. Lots of these words are used throughout this newsletter.

**Independent Living Fund (ILF)** Payments made to disabled people so they can employ PA's or a care agency to help them with personal and domestic tasks. The money comes from national government. To be eligible you have to receive High Rate Disability Living Allowance and a certain amount of funded social care from your local authority

**Direct Payments** Local council payments for people who have been assessed as eligible for help from social services, and who would like to arrange and pay for their own care and support services instead of getting them from the council. Legislation is being developed to **extend** Direct Payments to those who don't have capacity to agree or manage the payment themselves.

**Individual Budget or Personal Budget.** A **Personal Budget** involves a clear allocation of social care funding from your local Authority. This could be managed by councils or another organisation on behalf of an individual or paid as a direct payment, or a mixture of both. An **Individual Budget** is similar but can include a number of funding streams, not just social care.

**Indirect Payment** See Direct Payments above – legislation required to make this possible.

**Individual Support or Service Fund** When a service provider agrees to hold and spend someone's Individual Budget on the understanding that it will be spent according to his or her individual plan and kept in a separate bank account.

**Agent or Support Broker** If an individual doesn't wish to manage their own money directly but wants to keep some level of choice, another person can manage it on their behalf. This can be someone like a family member, friend, Trust group or a support broker. A support broker can also help the person think about how and where they might get their support.

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**Circles of support** A group of people, often family members and friends, who meet together on a regular basis to help somebody get the life they want. A circle of support will advocate for the person to make sure they are getting the right support and the things they are entitled to.

**FACS (Fair Access to Care Services)** The eligibility criteria used by all local authorities to decide whether a person's needs are critical, substantial, moderate and low. The local authority can then decide which social care needs are eligible for them to pay for and provide

**In Control** In Control is the lead organisation developing self directed support. It has led the way in piloting individual budgets and continues to produce lots of advice and guidance.

**Person centered plan** A process of life planning for individuals which puts them at the **centre** of the planning process.

**Resource Allocation System (RAS)** This is where the local authority looks at a person's needs and calculates what they can get. It makes the way social care funding is allocated much more transparent and gives an idea of funding you have to help start planning.

**Self assessment** A questionnaire completed by the individual (with support where needed) that identifies that person's support needs. From this the person is told how much their social care individual budget is likely to be (see Resource Allocation).

**Support plan** A Support Plan describes what a person wants to change or maintain in their life and how they will use their personal budget to make this happen.

**Self directed support** People who are eligible for social care knowing what they are entitled to and controlling the way they use their money to get the support they need the way they want it

**Total transformation** This is when a local authority moves from piloting individual budgets and starts offering Individual or personal budgets to all their current and new adult social care service users.

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## Self Directed Support and Families

### Victoria at Kings Cross

Self directed support is not new – it's been happening in different ways for many years. This article by Jean Willson shows how two families supported their daughters to get their own home 17 years ago.



Sandwiched between Lubetkin's huge tower blocks, only three minutes from Kings Cross station, sits the bungalow that my daughter, Victoria, has lived in safely and successfully for the last seventeen years.

Desperation made us, with another family, rescue our daughters from Social Services residential care and set them up in a home of their own. Both women had learning disabilities and multiple disabilities, including complex health needs. This was one of the first schemes to give independence, choice and control to two very disabled women.

Our two families were pioneers, innovators, and prepared to take risks. Opposition was high, particularly from medical professionals. At that time they refused to be part of our planning, as they stubbornly believed in the medical model for support. Social Services told us we could plan for the house, as long as it did not cost more than what they were paying for their residential care.

Over twenty years ago, as family carers we instinctively used a 'Person Centred Approach' as our starting point when planning how and where our daughters should live. As both women were without words, it was very important that they had choice and control over how they lived. We wrote Victoria's 'Speaking Book' which illustrates her choices, likes and dislikes, and gives directions to be followed. A tenancy for a new three bedroom bungalow was offered from the council, and a service provider was chosen. The funding came from Social Services, The Independent Living Fund, and their benefits.

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Kathy and Victoria moved into their own home in March 1991, and we were excited but terrified. We were prepared to take the risks, but would it work?

After just one week, not only were our fears allayed, but there were dramatic changes in both women. Victoria's constant screaming was slightly diminishing, and she showed signs of wanting to feed herself. The effect of not competing for attention and having one to one staffing throughout the day was showing! Over the next few months, both women blossomed and they began to develop new skills. As parents, for the very first time in our daughters' lives we were able to relax and were positively welcomed as guests and partners in planning every aspect of their lives.

There have been many difficulties over the years. Two service providers did not have their contracts renewed; repairs were neglected in the house forcing the tenants to live elsewhere for six months. Sadly Kathy died after four months, and we had to find another house mate, Lisa. Constantly maintaining high standards and motivating the team is difficult. Regular serious health concerns and hospital admissions for Victoria are stressful. Periodically, the service contract with Social Services & Health is debated intensely as "this is a very expensive package!" But Victoria and Lisa continue to be happy, and provide excellent role models.

To us, the additional workload - the meetings, negotiations, challenging the system - just had to be assimilated into our normal home/work life. Most families with a member with a learning disability are already used to doing this! What is important it Victoria has a better life!

As we get older, we have actively encouraged Victoria's advocates to take over. Her family now have to work hard at getting the balance right; looking after ourselves, letting others participate - but still really enjoying the company and life of a very remarkable daughter.

### What is an Individual Budget or Self Directed Support?

Avril Watson works in the Self Directed Support Team at Barnsley Metropolitan Borough Council. Barnsley is one of 13 councils piloting Individual Budgets in England. Over 100 local authorities have now signed up to self directed support for social care funding. In the article below, Avril explains more about how Individual Budgets or self directed support works.



An Individual Budget or Self Directed Support is designed to help people to take control of their own social care budgets. It is made up of money used by Social Services to help people who need support as well as a range of other funds. It is more flexible than just a direct payment (see *Is'haque* and *Direct Payments* on pages 18-19)

**An Individual Budget is not new money and people who use it still have to be assessed to find out if they are *eligible* for support. Local authorities work out if people are eligible for support they pay for by a process called Fair Access to Care (FACS).** The FACS process looks at an individual and their carer's needs and works out whether those needs are critical, substantial, moderate or low. Each local area then decides which of these needs they will fund.

If someone is eligible for support with their social care needs then an Individual Budget means that person can manage their support and choose the services and support that suit them best.



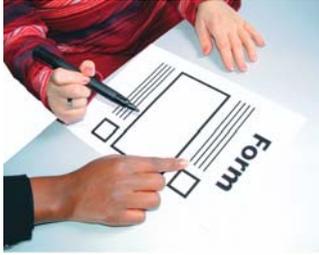
The person is at the centre of the all the planning as they understand their own needs the best.

The person is told how much money they can have after the person has completed a self assessment questionnaire.

The persons self assessment will be checked against the Resource Allocation System (RAS) which is the amount of money the person will be given for their support.

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Each box the person ticks on the self assessment questionnaire has a point and each point adds up to an amount of money. Someone adds up all the points and sees how much money you will be able to get as an Individual Budget to plan with.

The person is told by letter how much this money is and that they need to write a support plan to say how they are going to spend the money.

The support plan needs to be agreed by Social Services before the money is given to the person.

Social Services have a support plan checklist that they check all support plans against to make sure that it has got the things in it that make it a good plan..



### **Support Planning**

One of the things that the person will need to do to be able to get and use an Individual Budget is to make a support plan.

A support plan tells people important things like:

- Who the person is and what is important to them
- What support the person needs and who will provide the support
- Who's doing what
- How the person is going to stay in control
- How much support will cost—making sure that the person does not go over the budget they have been given.



In Barnsley, we have a Support Planning Guide that helps the person think about what needs to be in their support plan.

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People can write their own support plan if they are able to, and they can also get help from people like

- ✓ Their family, friends, or neighbours
- ✓ Support Brokers
- ✓ Care Managers
- ✓ Person centred planning facilitators
- ✓ People from other organisations e.g. Age concern etc.

Above all, it should be people that the person chooses and who they trust and who can help them think through the different support he or she may need and how they would like it provided.



Overall, good support planning should make sure that the person has a lot of control over how they spend the money to meet their needs.

### **How the money in an Individual Budget is made up**

The money that goes into a person's Individual Budget might come from different sources, including:

**Community Care Budget allocated through RAS** – the kind of money that is spent on funding places in residential care, supported living, day services and other kinds of social care.

**Supporting People** – money to help people live in a house or flat

**Independent Living Fund (ILF)** – this is money to help disabled people live in the community

**Disabled Facilities Grant** – this pays for change to a person's home like a stair lift or a ramp.

**Integrated Community Equipment Services** – this pays for equipment the person might need, like a raised toilet seat or a grab rail.

**Access to Work** – this is money to help a person get a job

The person can use their Individual Budget in a way that makes most sense to them as long as they are meeting the needs stated in their support plan.

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In Barnsley we offer individual budgets to:

- Adults (age 18 and above) with a physical disability and/sensory disability
- Adults (age 18 and above) with a learning disability.
- Older people (over 65)
- People with mental health support needs
- Young people with a disability who are in transition
- Family carers



### **Managing your Individual Budget**

The person has choices about how they manage their individual budget.

At the moment the choices are:

**A Direct Payment** – an amount of money held in a separate bank account by the person to employ a personal assistant, agency support or to buy a specific service.

**An in-Direct Payment (agent)** - the agent is someone the person trusts to look after the money given as a Direct Payment on their behalf in a joint bank account. Often this 'agent' may be a family carer

**Direct Payment – A Trust** – can be a formalised Circle of Support.: A group of 3 or more people who work together to look after the persons Direct Payment money.

**Support Broker** can be someone who helps you work out how you are going to get the support you want from the money you are given

**Individual Service Fund** – Is an Individual Support Provider (organisation) e.g. Mencap who looks after someone's money in a separate account, (which must not be mixed in with organisation's finances), and is used **only** for the person's support e.g. own staff members etc. This may be particularly good for those people without family or close friendships.

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**The Care Manager** may be the best person to look after someone's money – but this will probably be for only a few people who will probably need lots and lots of support that can be complex to sort out.

### Is there anything that the person can not spend their individual budgets on?

The person must use their individual budget to meet the needs they said they have when they ticked the self assessment questionnaire.

They can be flexible and creative about how they meet those needs,



### **BUT ...**

- It cannot be anything illegal or immoral.
- It cannot be used to pay for a nursing home or residential care home. (This is a Barnsley decision and it not true of all Local Authorities.
- It cannot be used to pay for support from someone who might put your safety at risk.

**in  Control<sup>®</sup>** For more information about any of self directed support and individual budgets, please go to the in Control website at [www.in-control.org.uk](http://www.in-control.org.uk). More information on in Control later in this newsletter

### Kieran's Story

The following story has been taken from *Self Directed Support, People's Stories, Volume One*. It is part of the collection of stories put together by the Self Directed Support team in Barnsley to show how people have been taking control locally.

#### ***Kieran's mum and dad talk about the family's journey so far.***

Kieran is 39 years old and has severe learning difficulties. Kieran used to go to a respite centre for a few weeks a year; we didn't get any choice about the dates but were told when they would be. He also goes to a day centre which he still enjoys.

Things became difficult with the respite service – he always seemed to be poorly whenever we went away or we would get telephone calls to ask us to go in – so it was no respite.

We were already getting support from the Independent Living Fund and the social worker spoke about Direct Payments. We decided to employ some carers to come to the house to look after Kieran while we go away.



We now have two carers and four bank carers for emergencies. We had some help from the support service and now we can manage it on our own. Kieran is so happy and we feel so much more settled now and able to go away. Kieran has no disruption to his routine.

We recently went on a cruise and we did not worry as we knew Kieran had been well looked after, going to the pub and having a good time. When we returned Kieran looked ten years younger!

We are so happy – we wouldn't change a thing. Our plan for the future is for Kieran to remain living in his own home with support, and for us to move out when we retire. We never thought this could happen but now it can.

## Ben Pelham's Story

Ben Pelham and Charlotte Morse's story helps to show how having a good, person centred support plan and the flexibility of an Individual Budget can make a big difference to peoples' lives.



Despite constant appeals to children's services for help it was to no avail and both Ben & I had reached breaking point by the time he reached his 18th birthday. Thankfully, adult services recognised our critical situation and Ben was offered the opportunity to be one of the first six 'guinea pigs' with a learning disability for the Individual Budget (IB) Pilot scheme in Essex.

The whole experience, from the (self) assessment through to the final support plan, was totally different from the experience we'd had in traditional services. We were both involved in the whole process from the beginning: Ben was at the centre of everything with the emphasis being on what he would like to change in his life and how to go about achieving his dreams and aspirations rather than dwelling on the negative aspects as had always previously happened; and I (mum), who knows him best, wrote his support plan.

### Using Ben's Individual Budget

Ben's Individual Budget has mainly paid for him to have a PA (personal assistant) to support him to learn what he needs to live independently, to help him feel safe when he goes out and to support him to become involved in the community and find new friends. It has also paid for him to have counselling to help him deal with his experiences of being severely bullied as well as guitar, dance and drama lessons.

Other than that we have not been able to be as creative with his money as we would have liked as he receives a top-up from the ILF (Independent Living Fund). This unfortunately can severely restrict creativity in the use of Individual Budgets as the laws surrounding the ILF insist that the entire care package be spent on 'care' (i.e. a PA). Hopefully, as time goes by the ILF will be able to change these restrictions to become more flexible.

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It has now been a year since Ben has had his Individual Budget & not only has his life changed beyond recognition, but mine has too. That vulnerable child who had been so bullied that he had not an ounce of confidence and who wouldn't even leave the house is now a young man who not only takes himself off alone to his new found job every weekend, but will stand up in front of audiences of 200 people to tell his success story! He has learnt many of the skills he will need to live on his own, has increased his circle of friends and found himself a girlfriend.

As for me, I am no longer constantly stressed from having to get home from work in time for his return from college or be obliged to leave him home alone during the holidays, as his PA is always there for him when I am working.

The changes that have resulted for Ben and others by having more choice & control in their lives has been so impressive that a group of us, have set up a social enterprise, trained as a peer mentors and support planners and now guide other people through the Individual Budget process.

Ben and I also travel the country telling Ben's story and informing others about Self Directed Support. So not only has Ben's Individual Budget improved both our lives, it has also given us both a whole new career path - one that is not only fulfilling, enjoyable and worthwhile but one that we are both absolutely passionate about.



### **'Top Tip' for other families....**

For anyone considering taking up the option of an Individual Budget all I can say is: *'Reach for the moon and if you only get half way there, you're still further along than if you didn't try at all'*

## The Harvey Family's Story

George Harvey explains how he's been able to build up a team of support around his son using a mixture of Direct Payments and ILF. The changes that have followed have transformed the life of the whole family.



My name is George Harvey and I am 75 years old. I live in Derbyshire with my wife, Brenda, and our son, David, who is 43. I applied for ILF after coming out of hospital having had a heart attack early in January 1998. This crisis situation was brought about through 24 hour caring for David, who has health problems along with a severe learning disability, and being awake sometimes for over 30 hours as he has difficulties sleeping. Although the extra care provided through the ILF helped us cope better, after three years we were still in a crisis.

In January 2001 I was in the local library and saw a leaflet for Direct Payments. I applied in January 2001 and we received our first payment in May 2002. It took 18 months of taking a person centred approach to convince the local authority that David and his family had special needs. Many meetings were held in our house: David had his own independent advocate and Brenda and I had our own independent advocate.

Things have now changed in the Harvey household and they have progressed every year since 2002. For example, in 2002 David attended his day service for only 218 days and in 2007 he had a 100% attendance record at the new day centre.

We have tried David going on holidays with Jennie, his main carer, but he wouldn't go to bed. Jennie tried him sleeping at her house with the same result. In October 2007 Brenda and I booked a long weekend away with Jennie coming into our house for the weekend and it worked. It also involved Sue, one of David's other carers, staying the night (just in case!) We had a good holiday – our first since 1991.

There have been many challenges along the way. Our first challenge was convincing the care manager that our problems were not of our making – hence getting two independent advocates!

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The other big challenge was badgering for David's health needs to be addressed which took six months of hard work with the community nurse visiting our house three or four times a week. The nurse's role was to navigate and accompany David, Jennie and myself on visits to hospital consultants and so on. Brenda was unable to make these visits through stress, so having Jennie around was of great help.

Jennie has been working with David since September 2000 and Sue since 1999. They have been the backbone of the care team of 5 self-employed carers all working for David but benefiting all the family. David has recently started to go to an Irish bar with one of his carers to listen to the Irish music he likes. He is living a life which reflects his age. Brenda and I were unable to provide his needs which resulted in David losing his skills and they have now returned. The list is endless of how all our lives have been transformed now we are IN CONTROL.

This is a very brief outline of how we have changed things around through taking a PERSON CENTRED APPROACH. David likes his home and our aim is to ensure that he remains in it. It's a home he has enjoyed for the past 28 years, in a community he belongs to and which he knows.

### **Top Tips**

- It's never too late to change your lives.
- Always prepare and write down what you want to say in meetings. Try to have someone, like an independent advocates as support
- Keep reviewing how things are going and make changes to keep moving towards your goal
- Joining a carers group does help. You support each other and you share information. Each carer usually holds a bit of information different to someone else and sharing does benefit each other.

## Is'haque and Direct Payments

Kauser Ahmed describes how her son and her family's lives were improved once they started using Direct Payments – although she also highlights some of the inflexibilities around them.



When my son, Is'haque, was offered Direct Payments at the age of 18, I was a little suspicious as well as delighted. Why would Social services want to let go control over when, where and by whom my son should be cared for?

At that point I had never heard of 'In Control'. My son's file had just been handed over to Adult services and I had hoped that they would just take over my son's carers' costs. The proposal that I should take over the budget for my son's short breaks took me by surprise.

After what seemed like the most complicated calculations involving heaven knows what criteria and hard work between the social worker and the newly appointed 'Direct payments co-ordinator', I was finally told to open a new bank account in my son's name with myself as the person who signs, as payments would start being paid. And so they did.

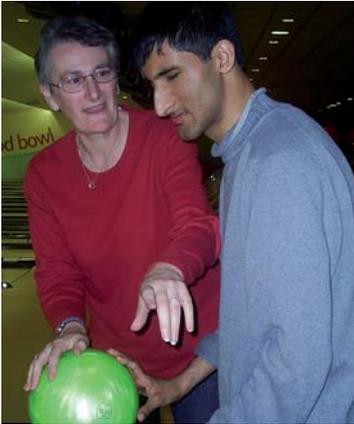
It was soon obvious that this was the best thing that could have happened for us as a family. The Direct Payment allowed more care hours than my son had been receiving previously from Social Services because the hourly rate had been calculated as a average figure from three different providers. Additionally, I was able to pay the carers more per hour than they had been receiving from social services.

Meantime, I had to register my son as an employer with the Tax Office, sort out Pay as You Earn (PAYE) and National Insurance liabilities and issue carers with a contract of employment. I was familiar with PAYE and NI systems as my husband and I had our own business with several employees.

So, after seven years how would I assess the impact that direct payments have made to the quality care and welfare of my son? The answer is mixed.

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It's been important to be able to reward the most important people in my son's life by paying them rates that reflect the responsibility of looking after such a vulnerable and complex young man. Hours can be arranged more flexibly to meet the needs of the family without having to make calls to social services. As my son is not a morning person and likes a 'lie in', carers can come in later and stay later. He can choose to stay at home and listen to his music if the mood takes him.

However, there is a serious problem with the very basis of how direct payments can be used. It is strictly for the payment of care, and that is interpreted in a narrow and strict way. It does not pay for activities. The rationale is that the public purse does not pay for other adults of the public to access leisure, social or educational provisions, but then the majority of the public do not have the barriers that face those with learning disability or other exceptional cognitive or physical challenges.

Direct provision by social services takes as given that there should be varied activities such as yoga, music and art. My experience is that these provisions are rarely available for people with learning disabilities in the wider community. Where they are available, they can be quite expensive and this is not covered by Direct Payments.

In addition, there are the formidable bureaucratic requirements of keeping detailed accounts for Social services. Many local authorities have details of local Direct Payment support groups who can administer payroll and help with contracts etc. for a small fee. Being a carer for someone with learning disability is already a full time occupation and not everyone wants to become a human resources administrator as well.

All in all I would give Direct Payments a score of 7/10. What is now required is increased flexibility and simpler implementation. Direct Payments need to evolve further.

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### West Lancs Peer Support Group



Les Scraife describes how the West Lancs Peer Support Group was set up by parents to help each other manage their Direct Payments. The organisation has since grown to support many more families to be more in control. It offers a model to help families with individual budgets



#### What is Peer Support?

*'Self help is founded upon the principle that people who share a disability have something to offer each other which cannot be provided by professionals'* (Clarke Institute, 1997).

Carter (2000) describes Peer Counsellors as *'people who have experienced emotional difficulties and are interested in helping others with similar difficulties. By listening empathically, sharing their experiences and offering suggestions, Peer Counsellors are uniquely able to help others like themselves. This approach promotes a wellness model which considers people with disabilities to be normal, as opposed to a medical model which considers these people to be sick'*. This is the model the West Lancs Peer Support Group have based their model on.

#### Why we set up a Peer Support Group

Back in 2000 a group of us parents had struggled to get Direct Payments for our sons and daughters. Once successful, we were given the payments and left to get on with it. There was no support on offer at the time so we decided we would support each other. We met up once a week to compare notes on filling in the various forms for auditing the payments, as well as things like time sheets, pay slips and expenses sheets. We have since designed far simpler ways of recording the same facts with less work that we give to all recipients of Direct Payments that we support.

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### Development of the Group

As the group grew we decided to form ourselves into an organisation and go for small pockets of funding to get established. We decided this because we could see Direct Payments were not being taken up through a lack of support. As soon as the support was available, direct payments took off in such a way that Lancashire is now one of the leading counties for the take up of direct payments.

Since we started we have assisted hundreds of people to both access and manage direct payments and ILF. We help them set up a bank account, get a suitable PA through our internet database ([www.lancs-pa.org](http://www.lancs-pa.org)), support them on the admin work of managing the payments and preparing accounts for audit. We are always here to deal with inquiries and visit people in their homes on review of their service package or assessments.

### Hopes for the Future

For the future we see an even greater need for Peer Support. Given the drive to Personal Budgets more affordable support will be in demand. Personally, I do not see 'professional' brokers being a success. I think support from people who are already using direct funds will be more acceptable to people with disabilities than any form of 'professional' support.

Our hope is for Peer Support to be adopted nationally. We have a plan set out to drive this and are speaking to two national organisations to form a partnership to achieve this.

Peer Support is a simple concept but very effective. It's about people already involved in their family disability issues supporting other people in the same position to take control of their lives and move forward to better things.

### Top Tips for Families

- Make sure your assessment or review is 'needs led'. If you are not sure, ask someone to support you at the assessment or review.
- Read up on the *Carers and Disabled Children Act 2000* and the *Carers (Equal Opportunities) Act 2004*. There is valuable information in this Act of Parliament on your entitlements.
- Finally, form groups to help each other. It's good to meet up socially to support each others' emotions and solve problems.

# Valuing People SUPPORT TEAM *Newsletter*

## Self Directed Support and Families

### In Control or out of control? Victoria's Story

Victoria has moved into her own home with the support of her mum, Jo, and her circle of support. Victoria is using self directed support to get the help she needs, and as Jo explains, sorting things out has had its ups and downs!



Victoria is 20 and has a learning disability. She has had a circle of support for four years who have been helping her plan her life and realise her dreams. Victoria's dream was to share a house with a friend, however due to circumstances this couldn't happen. Her dream changed slightly but she decided she still wanted her own house.

Victoria had been living away from home for a year due to my health problems but her circle still met and planned. The idea of Victoria having her own home was put to social care who said a definite NO due to cost. Having seen other examples of people in supported living and residential care who had little or no say in their lives, we were not going to be put off so planning continued.

During this time I attended a Partners in Policy Making Course, which reminded us of Victoria's dream of an ordinary life. I'd heard of In Control and self-directed support, so after lots of research we decided to go for it. Then I heard that Cambridgeshire were going to pilot self directed support so we jumped in feet first. If this was the way to secure funding for Victoria to have her own house with 24-hour support we were in!

The pilot started in February 2006 with presentations, real stories, and planning - it all sounded great. We now had to find accommodation and this in itself proved to be the first major hurdle. Victoria's name was put on South Cambridgeshire District Council's housing list. We filled in lots of forms and went to many meetings only to be told she couldn't have a tenancy due to her lack of capacity. Not to be put off, we did everything we could and used supporting documentation from *Valuing People*, *the Disability Discrimination Act* and *the Mental Capacity Act*. The Council had barristers go through the documents to try to prevent this happening but Victoria and her circle of support won.

# Valuing People SUPPORT TEAM *Newsletter*

## Self Directed Support and Families



On November 17th 2006, Victoria went to sign for her keys. Her budget was an agreed amount of money as the starting point and it all needed to be spent on 24-hour support, with lots of natural support to prop it up. We approached 3 agencies as we didn't have enough time to advertise and employ workers directly.

Victoria moved in January 2007 with live-in support from an agency. It was a disaster and after only 6 weeks they were dismissed and I had to step in. I had to give up my job, my relationship was put on the back burner and it was back to the drawing board again!

We approached other agencies to find three staff to work shifts but there was not enough money in the budget. Victoria's circle of support met many times to work out the finances, but whichever way we turned there was not going to be enough money. In August, we placed adverts for staff and after interviewing we recruited 1 full-time and 2 part time workers. However, one person left shortly after and another reduced her hours due to family commitments. I now support Victoria for more than 60 hours a week covering the shifts not covered – and we're advertising again!

This may all seem quite negative but on the plus side Victoria lives in an ordinary house in her community, has choice and she has really good neighbours. Her neighbours have been to her birthday party, one gives her vegetables from their allotment and another wants to learn sign language to understand what she's signing. Victoria also helps them if they're not well by putting the bins out, or doing some shopping. She goes to aqua aerobics once a week at the local swimming pool and she's joined the village library and entertains friends.

Victoria is happy, healthy and loves her house but the cost to me is huge. It's been a hard first year; we've learnt a lot, cried a lot, and laughed a little.

### Service Providers and Individual Budgets



Service providers can do a lot to support people with learning disabilities and their families to have more choice and control about how they use their Individual Budget. Sharon Clare, an Area Manager with Southdown Housing Association explains some of the different ways the organisation have supported people.



Southdown Housing Association (SHA) is a not-for-profit organisation working across Sussex to support people with learning disabilities and other vulnerable groups. One of the local authorities that we work with was a pilot site for In Control and is now an In Control Total Transformation site.

At Southdown we have been working on how we meet the In Control agenda for nearly 2 years and we believe it offers an exciting opportunity for people with learning disabilities and their families. It fits well with our values of personalisation. We have found that there is no ‘one true way’ when it comes to working with In Control as each individual’s circumstances and needs are unique and unique solutions are needed for people to live the lives they want.

Some examples of how we have responded to In Control are:

- We work with one family who hold the individual budget on behalf of their daughter ‘Sarah’. Sarah’s family bought a flat and employed a small team of personal assistants (PA’s) to work with her. The family found that managing some aspects of the package was challenging, such as the PA rota and being on-call 7 days a week. They also found it hard to know how to advise the PA’s on how to support her. Southdown’s solution was to provide one of our Managers for 3 hours per week to arrange rota cover, supervise and support the PA’s, arrange training and to provide some emergency staffing cover from our own staff teams. The Manager also meets with Sarah regularly to get her feedback and ideas on how she wants to live her life. The family remains in control of the budget with Sarah and continue to be the employer.

# Valuing People SUPPORT TEAM *Newsletter*

## Self Directed Support and Families

- We offer a Brokerage service where we will support an individual and their family to find the support they are seeking; this might be from another provider or employing their own P.A's. We are also developing a housing brokerage service and have a shared ownership scheme.
- Southdown have a range of supported living schemes where we provide a core staff team and management, purchased using the individual budget. Each individual is then free to purchase additional support from whomever they choose using the remainder of their budget. Within this model we will work with individuals and their families in many different ways. They are able to have as much or as little input as they feel able, for example, some families hold the individual budgets and do all the invoicing whilst for others we will hold the budget in an Individual Service Fund.
- We hosted a conference in December for local families called 'Making Sense of it all'. The conference included workshops on In Control, benefits, discretionary trusts and wills, community building to name a few. We invited local providers and other organisations to have stalls to show families the range of options available. The feedback was very positive but it was evident that many families had not been given as much information as they needed about In Control in order to make a decision about the future care and support of their relatives.

### **Top Tips**

- Don't be seduced by the cheapest price or the most expensive – this is not always an indication of the quality of the provider.
- Taking on a 24-hour In Control package is a big responsibility and time commitment, if there is one bit of the package that you don't want to do or feel you are unable to do there are always providers out there who can help.

## Making A Change In My Front Room **in Control<sup>®</sup>**

Caroline Tomlinson and her family were one of the first families to be involved in the In Control project. Caroline now works as part of their core team. Here she describes the difference that taking control has made to her life and to the life of her whole family.

It's been an exciting 5 years being involved in the self directed support journey. In early 2003 I got involved in the early thinking about in control because our son, Joe, was suffering the wrath of the human service system; his life was going from bad to worse and as a family we felt totally out of control.

Early thinking in Wigan enabled us to embark on the first real pilot of self directed support. Self Directed support was indeed the next step and push certainly needed for people with learning disabilities in this country. Much of this early pioneering work with direct payments was being led by the independent living movement which had made a huge difference to people with physical disabilities - it was now our turn!

Joe was fortunate to be one of the young people on the first pilot and I can only describe the changes through being part of In Control as radically and phenomenally changing his life for the better. He now has a life not dis-similar (and perhaps even better) to his peers; going to college, work, owning his own house and car.

But what has it really meant for us as a family?



It has enabled us to be a real family again. For example, we can do the things that many people take for granted like booking a holiday, being spontaneous, going out on a Friday night, having friends round, supporting our other children in their hobbies, school life and social activities.

These may seem very ordinary, but prior to Joe being in control of his life we hadn't been able to plan much into the future, our other two children had a difficult time due to Joe's behaviour, and our home and family car was continually being damaged.

# Valuing People SUPPORT TEAM *Newsletter*

## Self Directed Support and Families

Many of these issues arose because Joe was feeling angry and frustrated with his situation, which in turn manifested in the whole family feeling completely out of control.

But what has it meant for me? It has enabled me to take opportunities I personally could only dream of; the opportunity to work within the social care sector and influence the thinking of Government, Local Authorities and senior civil servants on behalf of individuals and families has been a complete privilege. I have been able to share the real experiences of people, who for the first time in many years I believe are starting to be listened to. This work has taken me the depth and breadth of the country as well as Portugal and Canada, and later on this year I'm doing some work in Australia. This has fulfilled my personal ambition to travel, but more importantly to create an international movement of change.

We need to create a future for the next generation; people will have much higher expectations and won't allow themselves to be lulled into a social care system which is neither responsive nor effective. There is still a lot more work to be done and I will use my window of opportunity to do as much as I can, to the best of my ability, which hopefully will open the doors to many more individuals and families. I know the outcome won't be perfect as the task is phenomenal but as long as it makes things better for more people that is at least a step in the right direction.



### ***The Essential Family Guide: How to help your family member be in control by Caroline Tomlinson***

***Tomlinson*** is a resource guide written for families who have a relative who needs support in order to have a good life. The book costs £10.00 (including postage and packing) and can be ordered from the In Control website at [www.in-control.org.uk](http://www.in-control.org.uk) or by ringing **0121 708 3031**

# Valuing People SUPPORT TEAM *Newsletter* Self Directed Support and Families

## Where To Get More Information

**in  Control<sup>®</sup>**

**In Control** is an organisation set up to help people get more control over their lives and the website is a good place to find out more.

Independent living = the goal  
Self directed support = the route  
Individual budgets = the vehicle

[www.in-control.org.uk](http://www.in-control.org.uk) General enquires 0121 708 3031

People supporting work with families within **In Control** include;

**Lynne Elwell** – from Partners in Policy Making – works with people and families and leads on citizen leadership.

[Lynne.elwell@in-control.org.uk](mailto:Lynne.elwell@in-control.org.uk)

Lynn James Jenkins who leads work with families and children

[Lynn.jamesjenkins@in-control.org.uk](mailto:Lynn.jamesjenkins@in-control.org.uk)

## DVD resources



***How to be in control: People using Individual Budgets talk about how to take charge of funding, support and life.***

Available from In Control Publications.

[admin@in-control.org.uk](mailto:admin@in-control.org.uk) 0121 708 3031

***Individual budgets: Living Your Life your Way. Individual budgets pilot programme.*** Available at [www.individualbudgets.csip.org.uk](http://www.individualbudgets.csip.org.uk) or email [ibpilots@dh.gsi.gov.uk](mailto:ibpilots@dh.gsi.gov.uk) or call Tina Virdee on 0207 972 3909

***Getting in control: People with learning disabilities and their families, Individual Budgets and Self-directed support.*** Available from HFT – Family Carer Support Service at:

[familycarersupport@hft.org.uk](mailto:familycarersupport@hft.org.uk) 0117 930 2608

# Valuing People SUPPORT TEAM *Newsletter*

## Self Directed Support and Families

### In Control Advice



**In Control Advice** was set up in November 2007 is to provide people and their families with information that will help them have more choice and control in their lives through self directed support. First we will work in Hartlepool, Hampshire, Essex, Cumbria, and the London Borough of Richmond to produce a range of information for individuals and their families.

The information gathered and produced will be shared through the National Learning Disability Helpline . An online advice area with step-by-step advice to guide people through all the steps of self-directed support will also be put on the In Control website.

If you would like further information on how In Control Advice is progressing you can contact the team for further information:

Lisa 07984 111315 Alison 07951 637247 Terri 07951 637276

### PLAN Federation UK



As part of its community innovation work, In Control is supporting the development of a family focussed and family led membership organisation called PLAN (Planned Lifetime Advocacy Network).

PLAN responds to two common family concerns:

1. What happens when I am gone?
2. How can I help my son/daughter have a good life?

PLAN supports families to build circles of support for disabled people that will ensure they are part of their community. It aims to support families to face challenges and be heard, as well as making sure they have the right information and guidance to plan for the future.

To find out more about PLAN, contact **Jane Ahern** at:

PLAN Federation UK, In Control Support Centre, 4 Swan Courtyard,  
Coventry Road, Birmingham, B26 1BU

Email: [jane.ahern@in-control.org.uk](mailto:jane.ahern@in-control.org.uk) Tel: 0795 646 5204

# Valuing People SUPPORT TEAM *Newsletter*

## Self Directed Support and Families

### ...Finally,

The personalisation agenda has enormous implications for family carers. Some of the Individual Budget Pilot sites have started to think more about how they might work for family carers in their own right. If you want to find out more you can contact:

Alison Reeve at [alison.reeve@essexcc.gov.uk](mailto:alison.reeve@essexcc.gov.uk)

Angela Todd at [angela.todd@gateshead.gov.uk](mailto:angela.todd@gateshead.gov.uk)

The Princess Royal Trust for Carers (PRTC) recently wrote that ‘...we must make sure that when we are ‘Putting People First ‘we are not putting carers second’. In summary the PRTC has said; ‘carers welcome personalisation, but increasing the independence of people with long terms conditions must not be at the expense of their carers’ independence and health’. We need to ‘apply the principles of Putting People First to whole families as well as individuals’.

As Valuing People Now works to make personalisation a reality for people with learning disabilities we need to ensure that families are fully included in making it work and that local authorities are supported to make sure this happens. This is a very exciting opportunity for people and their families to have more control over their lives.

Cally Ward

Valuing People Support Team

[cally.ward@dh.gsi.gov.uk](mailto:cally.ward@dh.gsi.gov.uk) or contact Carol Peacock 01623 812933

I would like to thank everyone who contributed to this newsletter especially all the families we shared their stories, views and photos. Once again a very big thank you to Dalia Magrill who helped edit this newsletter.



# Valuing People SUPPORT TEAM *Newsletter* Self Directed Support and Families

## And finally changes.....

The team would like to say a special farewell to the following people who have or will be leaving us shortly.....



### **Debra Moore**

Debra has been the Joint Programme Lead for VPST with Sue Carmichael for the past two years. She has also been the national lead on health for the team since 2003. Debra left the team at the end of March to work as a health consultant. We wish her the very best of luck in the future!



### **Rob Greig and Nicola Smith**

Rob has been with the Valuing People programme since it started and been the National Director for all of that time. Rob set up the original Valuing People team. He and Nicola Smith have been co national directors for the past 2 years.

Rob and Nicola both leave at the end of April to continue their work elsewhere. Rob will be the new chief executive of the National Development team.

Everyone sends them best wishes and thanks for their work now and in the future.

# Valuing People SUPPORT TEAM *Newsletter*

## Self Directed Support and Families



### **Gill Cameron**

Gill Cameron has been our workforce adviser for the past 7 months and is returning to her full time role at Leicester City Council. Many thanks to Gill.

*And a warm welcome to.....*



### **Mary Clifton**

Mary joined Sue Carmichael as VPST programme lead from the beginning of April. Mary works in the Care Services Improvement partnership and was most recently Director of CSIP's East Midlands Regional Development Centre.

Mary will also be leading on LINKS work and the Having a Voice programme as well as work with User Led Organisations. Mary will lead the Valuing People programme while Sue Carmichael takes a career break of 3 months starting in July.

We would like to welcome Mary to the team and wish her much success!