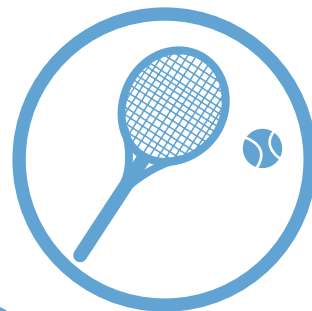


We Can Dream!

Ways of planning for the future for young people with autistic spectrum disorders



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We Can Dream! - about the project

The Foundation for People with Learning Disabilities, in partnership with the National Autistic Society (NAS), and a number of local authorities, has supported a small group of young people with autistic spectrum disorders and their families to have a meaningful life after leaving school.

We know that with the right support young people with autistic spectrum disorders can express creative ideas, dreams and hopes for their future. One way of doing this is to use person centred planning. Person centred planning is a way of planning all aspects of a person's life. The person is at the centre of the planning process and with support decides who they would like to help them and who can help them make the plans possible. This approach is particularly useful at transition because it gives young people a chance to say what their hopes and dreams for the future are.

Research evaluating person centred planning by the Foundation for People with Learning Disabilities and other partners (Robertson et al, 2005) showed that people with autism were less likely to have a person centred plan. This was because some of the processes in this approach were not easy to use with people with autism. In this project we have worked out ways to support people with autism better through the person centred process.

This booklet

This booklet is for young people and their families, friends and supporters to read and talk about together. It is based on the stories of four young people. We hope it gives you good ideas about what to do when you leave full-time education. It is not always easy to bring about changes – but with careful planning, time and the right people to help, things can happen.

Robertson, J., Emerson, E., Hatton, C., Elliott, J. et al (2005). The impact of person centred planning. Institute for Health Research: Lancaster University.

The young people's profiles

The four young people featured here all took part in the project. Big changes happened for some of them; others are still waiting for things to change. We hope their stories give you ideas about how you may want to plan or change things when you leave school or college.



Name: Marc
Age: 18

Where do you live?

I live at home with my mother and brother in Kent.

What do you do in the day?

I go to a post 16 unit for pupils with autistic spectrum disorders but will be leaving soon and want to start planning ahead for my future.

What is important to you?

My passion is music and I want to pursue a job working in the music industry or in a record shop. I would like to leave home and live with friends in the near future. I want a normal life doing normal things.

It's important I keep close contact with my family and some of my friends from school, my routines and my daily activities.

What do you like doing?

Being with my friends, going out. I want to go out more in the evenings and weekends when I leave home. Listening to music, gardening, cooking and shopping.

What don't you like doing?

Bike riding and being in noisy places.



Name: Melanie
Age: 19

Where do you live?

I live with three other young people in a house with support in Essex. I moved there a few months ago.

What do you do in the day?

I left school last year and now I go to my local college, doing a life skills course. I am also doing a childcare course and spent time in a primary school.

What is important to you?

I want to keep fit so I go swimming three times a week. I really like having my hair styled every Thursday and having my nails painted.

What do you like doing?

I like meeting up with old school friends at a youth club every Thursday. I like being with small children and this is something I'd like to do after I leave college. I like being independent – doing housework like the washing and ironing and cleaning. I also like cooking Indian food and watching films with my housemates. I meet up with mum and dad every Sunday.

What don't you like?

I get scared and frightened of dogs. I also do not like insects so I need a lot of support if I see them.



Name: Fiona
Age: 20

Fiona's Mum says:

Where do you live?

Fiona lives with her family in North East London.

What do you do in the day?

Fiona has a very structured week that is made up of a range of activities she likes to engage in. These include art and photography classes and going to the health club where she is a member.

What is important to you?

Having people around Fiona who know her really well so that she does not get worried about things.

What do you like doing?

Fiona is a keen photographer and artist. She recently sold a piece of her artwork when it was displayed in a local art exhibition.

What don't you like doing?

Fiona dislikes changes in her life so it is really important to introduce new things very gradually.

Name: Crystal
Age: 21



Where do you live?

At home with family in London. I live with my mum, two sisters, brother, grandma and Rover the dog.

What do you do in the day?

I have two support workers who help me do things at home such as making my lunch, tea and drinks. They help with dressing and other personal things such as shopping, going to the bank, taking Rover to the park, swimming and going to music class. My mum, sister or brother also take me out and do lots of things that happen once in a while, like going on holidays.

What is important to you?

Living with my family, having my own space to do my own thing, being active, learning new things, good food and drink. I also like my mum to read to me and listening to music for relaxation.

What do you like doing?

Going to the park to run and walk, listening to music (Madonna) and stories on CDs and looking through catalogues. Exercise and relaxation is very important to me, especially swimming, having massages, saunas and jacuzzis. I also watch international football games, like going on car rides with mum and my sister, going to parties, listening to DJs and live bands and of course, going on holiday.

What don't you like doing?

Staying home when my mum goes away without me. Doing the laundry or household work. Being in crowded, noisy shopping centres. Going on hospital visits, getting my blood pressure checked.

Planning in advance

From working with Marc, Melanie, Fiona and Crystal we learned it was really important to plan well before you leave school or college. One young person was about to leave school and no plan was in place. This made her and her parents feel very worried about what was going to happen. For all the young people we used person centred planning.

What is person centred planning?

Person centred planning is a way of getting to know a person and helping them make plans for all aspects life. It is often used with adults with learning disabilities. The person is at the centre of the planning process and, with support, decides who they would like to help them to make the plans possible. This approach is particularly useful during periods of transition because it gives young people a voice to say what they want for their future.

The purpose of person centred planning is to give the person an opportunity to think about what they want from their life now, and in the future. The person is supported to make their own decisions and have more control over their life. There are a number of ways in which you can develop a person centred plan and there are numerous tools to support people to think about what a positive future will look like, and the steps to making it happen.

The key questions to think about in person centred planning are:

Who are the important people in a person's life?

These are the individuals the person wants to be part of developing their person centred plan and who can help them make things happen. These are the committed people in the person's life who know and care about them.

What are the person's strengths (or gifts)?

By finding out what the person is really good at and what people like about the person, it can help people think about the kinds of employment, educational courses, career paths, activities or future housing options the person may wish to pursue.

What is important to the person now and in the future (or dreams)?

This helps people think about what is important to them, and what they want from others to make sure those important things stay the same. It may also highlight what the person is not getting so that plans can be made to ensure things start to happen in the future. Learning about what is important to people can also help others to understand the person's preferences. Similarly, asking what a person's dreams are can be a creative way of providing ideas of what to pursue in the future.

What are the supports the person may need to make things happen to get the future they want?

Learning about the person's gifts and dreams will help people to identify key areas in which support is needed. Family members in particular find this useful as it means the conversations can explore ways to overcome obstacles. For example, if a person finds changes in an established routine hard to accept, this can be written into a detailed plan to be followed by all the people supporting the person.

What do we need to do?

This is also called 'action planning'. This is a way to ensure that those things the person wants to happen, to make a positive future, actually happen. This would include identifying the people who are responsible for implementing the plan with the person.

The planning process and people with autism

In order to make the person centred planning process meaningful for people with autistic spectrum disorders we have incorporated the SPELL approach by the National Autistic Society. That means the process has a clear **s**tructure (there are key questions to ask); it focuses on the person's **p**ositive attributes (their gifts and strengths); there is an **e**mpathetic approach (for example, using the means of communication that the person understands best); **l**ow arousal (see below) and **l**inks with the most important people and things in the person's life.

Adapt your language

It is generally understood that many people with autistic spectrum disorders find it difficult to understand abstract language. The language used in person centred approaches tends to use words such as 'dreams', 'wishes' and 'gifts'.

We found that using questions such as 'What do you think you are good at?', 'What things do you like to do?', 'What things make you laugh?' and 'What would you like to do when you leave school?' work much better.

Make sure planning meetings are not too busy (low arousal)

The person centred planning process is generally seen as being autism friendly as approaches tend to use lots of visual aids (for example, writing down on large sheets of paper the person's strengths or gifts, their dreams or plans for the future) so this really helps the person's understanding of what is happening. However, for some people too many visual aids can be over-stimulating. It is also important to think about how many people to invite to the planning meetings - too many people present can be stressful for some.

Recognise and value each person's special interests

Professionals and services often label people with autism as having 'obsessions' rather than talents and gifts. If we focus on these talents they can be used to support the person in a positive way.

Melanie's Plan

For **Melanie's** plan, the first thing we did was to list all the really great things (sometimes called gifts) about Melanie, as these gave her ideas about what she wants to do in life. We then asked her and her family to think about what she would really like to do in her life (sometimes called dreams). In order to make sure Melanie is safe and supported in the best way, we also asked what the nightmares are (or things that could go wrong or what you dread about the future). This is important as it helps to introduce a balance between independence and health and safety. For example, in Melanie's case she could not live without 24 hour support, but needs her own space away from everybody to do the things she loves to do on her own. This helped in the planning for her future housing.



Melanie lived away from her home town. She wanted to move back to her local area because she wanted to keep in touch with her old school friends and attend the local college where they go. She was also keen to continue attending the clubs and activities she did after school and during school/college holidays.

After getting Melanie's views, her circle of support (see pages 13 and 14) made an action plan that listed her goals and what actions the circle of support would do in the short-term (three months) and in the long-term (six months). Each person who attended the planning session agreed to do certain tasks to help her move forward with the plan. For example, her mother agreed to take Melanie to visit the college she wanted to go to. Her transition worker agreed to make a referral to the housing social worker.

Now, Melanie has left school and studies at the local college and has moved into a house with three other young people. She has managed to achieve important goals - to go swimming regularly and lose weight. Melanie is delighted that her plan has come true.

Crystal's Plan

Crystal did not like going to school because she was bored. During her last year at school, she was offered a day centre as the only option for her future supports. Crystal's mum, Rose, did not want Crystal going to a day centre.

Rose wanted Crystal to have a more fulfilled life. Rose attended a course on 'Families and Person Centred Transition Planning' provided by the Foundation for People with Learning Disabilities and Brent Council. Rose and Crystal learned about person centred planning and how this could help Crystal develop a positive plan for the future. They were assisted to develop an individual way of providing support to Crystal so she was in control.

Now, Crystal receives money from Direct Payments and the Independent Living Fund grant. She uses her money to hire personal

assistants to support her in various activities at home and in the community. At school Crystal did not use many words to let people know what she wanted: she used her behaviour. Since leaving school she is using more words to let people know what she wants. This spring Crystal took her first holiday with her family to Spain. Rose has been influenced by the way person centred planning helped her and Crystal stay in control of her future. Rose can now spend more time providing support to other family members and Crystal can do the things that she enjoys.

Fiona's Plan

Fiona should have left school last year but through her person centred plan it was agreed that she would stay at school for another two terms. This was so that her circle of support had time to prepare ahead of her leaving school – they had to plan a weekly schedule based on Fiona's interests and strengths as she was not going to use the learning disability services provided by her local authority. It also gave Fiona time to get used to the new people recruited to support her (paid through her self-directed support package) as they spent time with her at school.



How to get a person centred plan

If you live in England you should have a review and begin your transition planning in year nine at school. Many schools in England are adopting the 'Person Centred Review' process, adapted from the Essential Lifestyle Planning process (Smull and Sanderson, 2005). The outcome is for the young person to have greater involvement in their transition review and to be at the centre of developing a plan for their transition from school to adulthood. For further information go to www.valuingpeople.gov.uk

In Wales too you will start planning for the future in year nine at school. A careers adviser from Careers Wales will get involved. In Northern Ireland a Transition Planning Coordinator may attend your planning meetings. In Scotland you can do a person centred plan as part of your Future Needs Assessment.

Here are some things you may wish to do:

- Find out if your local authority has a person centred planning co-ordinator or facilitator who could help you.
- Remember your person centred plan includes all the things you do in your life including what you need to keep you healthy.
- Think about how you would like to record your ideas. Would you like to draw or write on big pieces of paper? Do you want to use photos? Do you want to make a book, CD or DVD?
- Make sure that people sign up to your plan and do the things that they say they will do.

Smull, M.W. and Sanderson, H. (2005). Essential lifestyle planning for everyone. Stockport: The Learning Community.

Bringing in people who know you best

It is so much easier to plan if you can do it with other people, usually those who know you best. These could be your parents and other members of your family, teachers and tutors, friends and other people you are in contact with. Some people have an advocate - this is a person who makes sure the person going through the planning process has a voice. Advocates are usually not related to the person and may belong to an advocacy organisation. To find out if there is an advocacy organisation in your local area, contact the advocacy support exchange (ARX) at www.advocacyresource.net

Circle of support

One of the most common ways of developing a person centred plan is to bring together a circle of support. A circle of support is a group of people who meet regularly to help somebody achieve what they would like to do in their life, for example, get a job, go on holiday or take part in a leisure activity.

It is useful to work on the relationship map (see page 14) as the first step in the process. Think about whether you would like to have a circle of support, who you would invite and where you would meet. You should decide where it will be held, for example, in your home, a restaurant or a cafe. Circle members sign up to any decisions made during the circle. Make sure everyone is comfortable in your meetings, including yourself, and that everyone enjoys themselves.

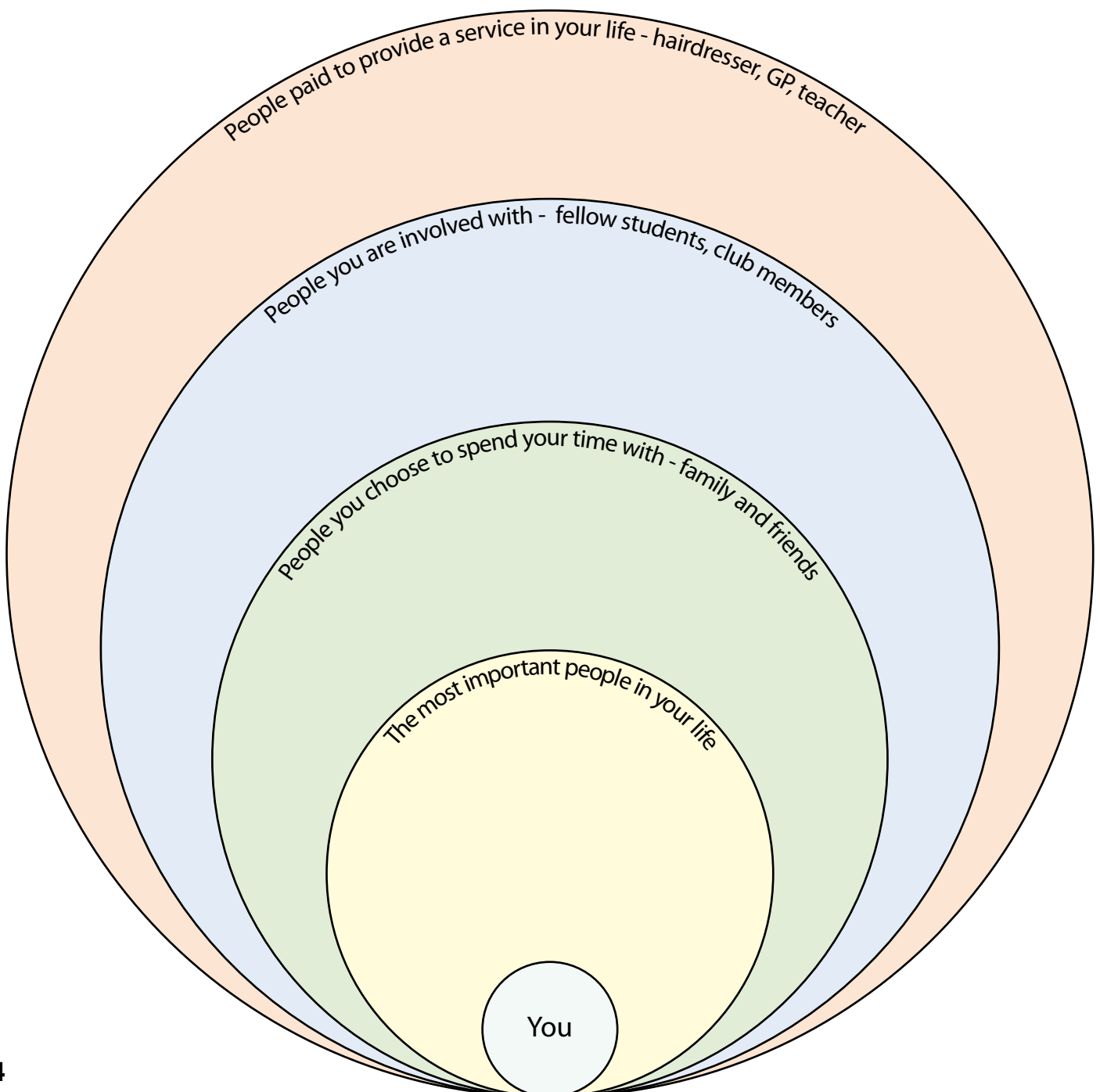
Melanie had a small circle of support to help her think about the future. Members were her mother, father, transition worker and key worker at the home she lived in. After the first few meetings the housing social worker joined the circle of support as moving house was something Melanie wanted to do.

Marc met with his circle at school or at the pub. He is still at school so the circle continue to meet regularly to make sure the plans are based around Marc's wishes.

Fiona and her family have a circle of support made up of her social worker and school staff. The circle of support identified her strengths and passions, along with what makes her feel safe and what could be the nightmares if she did not receive the right kind of support. By having a plan developed by those who knew her the best, it was agreed that she would remain at school for another two terms so they could plan her week in preparation for leaving school. It also gave the new staff time to begin to get to know Fiona in an environment that she felt safe in.

How to get a circle of support

- Sit down with your supporter (this could be a parent, teacher or social worker) and fill in the relationship map on this page. You need to list your family members, close friends and supporters and other important people in your life.
- From the list think of the people you would like to support you.
- Set a date, time and place to hold your first circle of support meeting. This could be in your house, at school or even in the cafe.
- Ask your supporter to help you plan the first meeting. You need to think about who will lead the meeting with you.
- In the first few meetings you may want to ask the questions on pages 8 and 9 as this will help you start thinking about the future.



Making it happen

Once you have thought about what you want to do and you have people to support you, it is time to make things happen. When you leave school or college, some of you will need extra help to make the most of your life. If you have been assessed by your local authority/social services as needing a care service, you may be able to get a Direct Payment or an individual budget. Not everyone wants a Direct Payment as they may prefer to have services provided by their local authority. If you have a social worker or care manager, invite them to your circle when needed so that they can make things happen (this is usually when funding is required).

Self-directed support/individual budgets

The Government is suggesting a new system of social care called self-directed support. In this system people will be in control of their support. They can be given money to pay for the support of their own choice. One of the existing models offering this approach is called In Control.

This helps people to get the support they need to do the things that are important to them. Some get Direct Payments or a resource allocation fund to pay for support instead of using a day service or going to college. Others use it to pay for staff to support them to live in their own home or to have a social life. This could mean employing a personal assistant to support someone going to a nightclub or on a short break. This is preferred by some people because personal assistants employed by the local council are often bound by strict working hours which do not allow for such flexibility. Some people do not want a Direct Payment and prefer to use the services and support provided by their local authority.

Some young people will be assessed by social services as not needing a care service. If this is the case, it is worth asking members of your circle to support you to make things happen. For example, if you want to work perhaps they may have contacts who can offer work experience or information about getting a job. They may also be able to support you in developing your social life if this is something you want to do. For example, if a circle member has the same interests as you, perhaps you could arrange to meet up, or email each other.

Fiona used the In Control model to plan her days after leaving school. Having developed a very detailed person centred plan, her social worker took it to the social services panel because she needed money to make things happen. She was allocated a set amount of money to continue to support her at school for an extra two terms and then to ensure she had an individual weekly schedule on leaving school with a team of personal assistants. The funding means Fiona can take part in various activities. It includes annual membership for her and her personal assistants to a local health club. With support, Fiona displayed some of her artwork at a local exhibition.



Fiona's artwork

Fiona's mother manages the funding and employs the personal assistants herself.

Marc's passion is music and he wants to pursue a job working in the music industry or in a record shop. Members of his circle have been supporting him to think about the best way to reach his goal. He wants to move out of his family home and into a flat with a friend from school. Marc and his family are currently being supported by his circle to challenge his Local Authority. This is because they are not supporting Marc's plans for the future.

Crystal has Direct Payments and an Independent Living Fund grant (ILF – see page 19) which she uses to hire personal assistants to support her in various activities at home and in the community. Her mother manages the money on her behalf and she has arranged with a local agency to pay the personal assistants. Rose also has an accountant to keep Crystal's finances in order.

How to get self-directed support/individual budgets

Here are some things to do, if you think you would like self-directed support:

- Talk to your friends and family about what you would like to do and why you want self-directed support.
- Ask your social worker about whether you can have self-directed support. If you do not have a social worker, contact social services and ask if someone can talk to you about them.
- If you are able to have self-directed support, the social worker will tell you how much you can have and you will agree how you will spend the money. You will have a special bank account.
- If you are able to have self-directed support, decide whether you and your family want to deal with the money and pay the personal assistants or carers or whether you would like an agency to do that for you. (You can still appoint your own staff if you like).

What's been the best thing about having a person centred plan?



'Getting a Direct Payment and funding from the Independent Living Fund. I can choose who works with me and plan my day according to how I feel. I can choose the hours I want support for.'



'Going to the pub for lunch and talking about my life. Hopefully, getting my own flat to live in when I leave school. Doing more things away from home.'



Fiona's mum states that if Fiona had not been given the opportunity to have a person centred plan she would be at home doing nothing. The local services were not suitable for Fiona so having an individual plan and receiving the money to support it has made a huge difference to the quality of her life.



'It was lovely, because people listened to me and now I live in a beautiful house with three friends.'

Useful information

Person centred planning

You can download 'My Personal Planning Book' by the Foundation for People with Learning Disabilities at www.learningdisabilities.org.uk

There is a workbook, 'Listen to Me', which you can get from the Valuing People website at www.valuingpeople.gov.uk/dynamic/valuingpeople137.jsp

There is a website designed, planned and run by people with learning disabilities to help others stay in control of their lives at www.handsoffmyplan.co.uk

See the Trans-active website for help with making plans at www.trans-active.org.uk/teenz/index.htm

There is a book called, 'Building Community Through Circles of Friends' written by Christine Burke in 2006 which you can buy at <http://www.learningdisabilities.org.uk>

Self-directed support

You can download 'An easy guide to Direct Payments: giving you the choice and control' from the Department of Health website at www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/Directpayments/index.htm

You can download 'An easy guide to Direct Payments in Scotland: giving you choice and control over your social work services' from the Scottish Consortium for Learning Disability website at www.sclld.org.uk/data/file/file_78_An_easy_guide_to_direct_payments.pdf

'Getting in Control: People with learning disabilities, their families, individual budgets and self-directed support' is a DVD for families. You can order it at www.hft.org.uk

In Control

In Control started work in 2003 to change the social care system in England. The old system did not put people in control of their own support or life.

In Control designed a new system - Self-Directed Support. The Government now wants all local authorities to change their systems to Self-Directed Support. You can find more information at

www.in-control.org.uk/site/INCO/Templates/Home.aspx?pageid=1&cc=GB

The Independent Living Fund (ILF)

The Independent Living Fund is open to applications from severely disabled people who meet its eligibility criteria and are permanent residents of the United Kingdom. The Independent Living Funds were set up as a national resource dedicated to the financial support of disabled people to enable them to choose to live in the community rather than in residential care. You can find more information at

http://www.ilf.org.uk/about_the_ilf/index.html

Personalisation

You can order or download a copy of 'Personalisation: a rough guide' from the Social Care Institute for Excellence at www.scie.org.uk

Valuing people now. (2009) Department of Health. These are the English government's priorities for people with learning disabilities over the next three years. There is a large focus on the personalisation agenda. It can be accessed at

http://www.dh.gov.uk/en/Consultations/LiveConsultations/DH_081014