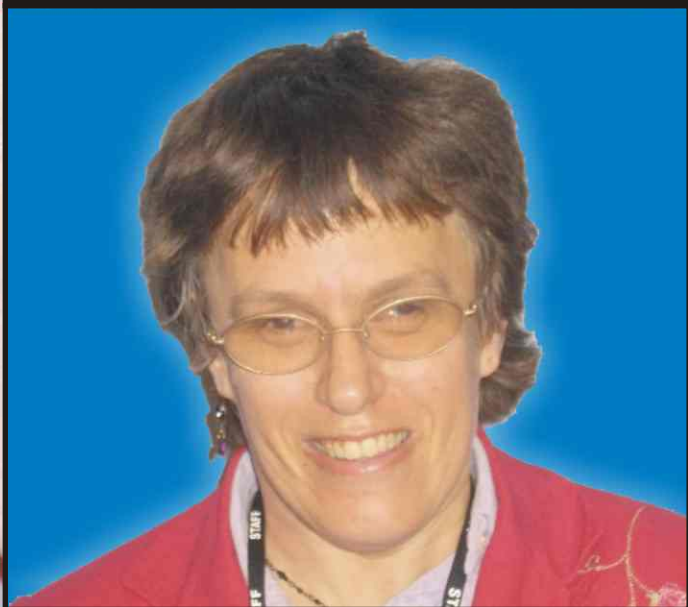


Community Connecting™

*Valuing
people with
learning
disabilities*



Nicola Smith - appointed as the new
learning disability 'tsar'. See page 04.



Issue 6 Autumn 2006



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Community
Connecting

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(A couple seeking advice on trusts for a
property for their son)

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*Valuing
people with
learning
disabilities*



Welcome

It is great to be able to start an editorial with such positive news. Nicola Smith's appointment, in May 2006, as Co-national director for learning disability in England is the most positive event that I can recall in the 32 years that I have worked with people with learning disabilities (see page 07).



Another extremely positive event was the Community Matters conference, held on 24th May 2006, presented jointly by Paradigm and **Community Connecting** magazine (see page 13). The conference marked **Community Connecting** magazine's first anniversary and Nan Carle made her first keynote presentation in the UK on 'Assets Based Community Development' (ABCD). In each issue since our launch Nan has written about ABCD, promoting it as a tool for connecting with communities. We believe that 'community connecting' is the fourth ingredient to successful support for people with learning disabilities. The other ingredients are person centred approaches, individualised services and strong advocacy. In fact we hold this belief so strongly that we chose to name this magazine '**Community Connecting**'. Another engaging presentation at the conference was made by Carl Poll who spoke about the 'Small Sparks' project. Carl reports on 'Small Sparks' on page 9.

In this issue we are delighted to present readers with a four page supplement on Person-Centred Planning. The supplement is an edited and revised version of chapter 2 of the second edition of 'Keys to Citizenship' by Simon Duffy and this version is published with the kind permission of the publisher, Paradigm.

Turning to a far less positive topic, **Community Connecting** magazine continues its anti-abuse campaign launched in issue 4 when I reported that the Healthcare Commission (HCC) was investigating allegations of abuse at the Cornwall Partnership NHS Trust. The findings of the HCC investigation were published in July in a joint report by the HCC and the Commission for Social Care Inspection. The report, which can be downloaded from the HCC website www.healthcarecommission.org.uk, describes whole systems failure which led to widespread endemic abuse at the NHS Trust. The findings of the Inquiry were reported on widely in the media at the time including in the Independent, the Guardian, the Mail and on BBC radio and television news.

Steven Rose
Editor

Contact: info@communityconnecting.co.uk

Government appoints Nicola Smith as first learning disability 'tsar'

Interview by Steven Rose

"I hope many other organisations will follow this lead and appoint learning disabled people to senior paid positions." Rob Greig, Co-national director: learning disability

VALUING PEOPLE
Support Team

Nicola Smith's appointment as the new learning disability 'tsar' must be the most significant event for people with learning disabilities since the publication of 'Valuing People' in 2001 and arguably the most significant event in a much longer period. Nicola will work as Co-national director alongside Rob Greig.

Ms Smith, 43, started work in her new post in May. She first became involved in the self-advocacy movement ten years ago, founding and becoming chair of a self-advocacy organisation in Sussex. She also served as a national assembly member of Mencap for two years. Nicola is the elected member for the southeast at the National Forum of People with Learning Disabilities and co-chairs her local Learning Disability Partnership Board.

Nicola's appointment was announced by Ivan Lewis the minister for care services, who said "It is important that we listen directly to the views of people with learning disabilities in making policy, commissioning services and providing care. Nicola will bring valuable personal experience to the job and will help lead the cross government agenda for those with learning disabilities. I wish her the very best of luck in her new post."



Nicola Smith

Rob Greig, Co-national director said: "The appointment of a person with a learning disability to such a senior and paid role shows that the government is serious about the 'Valuing People' commitment to giving people choice and control over their own lives. As a learning disabled person, Nicola will be able to make a powerful contribution to the national agenda in a way that I could not hope to. I hope many other organisations will follow this lead and appoint learning disabled people to senior paid positions."

Community Connecting interviewed Nicola, soon after her appointment, and put the following questions to her:

Q What is going to be the first priority in your new job?

A The first priority in my new job is to work on the closure of hospital campuses to make sure that people have better lives; to work together with, and talk to the people who actually live in the hospital campuses to make sure that their rights are heard.

Q What needs to improve most in the lives of people with learning disabilities?

A What needs to improve is that we need to be listened to. We are people in our own right. We might need more support, we might need more help but we are just like everybody else. We want people's lives to be improved so that they have the right housing and the right support for their needs. We also need to improve employment so that people can have paid work without the benefit system getting in the way.

We want to be able to do every day things, like being in the community and taking part in leisure activities such as going to the cinema, playing snooker, bowls, and going out for a meal.

We would like to have better healthcare; to give people with learning disabilities health assessments. If we have good healthcare support we can be the same as everybody else.

We also know that there is a lot of “hate crime” happening, this includes abuse in care homes. Some staff work in very bad conditions and they get frustrated.

Q Can you tell our readers what the main duties in your job description are?

A My main duties in my job description are:
To be able to talk to the Government, and to help people understand about policies, like the Valuing People White Paper and new policies that are coming out.

To help find out about people from advocacy groups, people from black and ethnic minority groups and from people who have high support needs.

To go to conferences and to find out and listen to what people say and take it back to groups and to be able to give presentations at conferences.

To listen to the Government and the Minister and to work alongside Rob Greig, the National Director for Learning Disabilities.

Q What achievement in your life (apart from being appointed as Learning Disability “Tsar”) are you most proud of?

A I was proud that I got a merit for my first NVQ Care Course. I was really proud that I managed to sit an exam after leaving school with no qualifications.

I am also very proud of setting up a self-advocacy group in my area. The group has been going for 10 years now. It is called Bognor and Chichester Voice. It was started because it was needed in West Sussex; there was nothing in our area. The group has been very successful in changing people's attitudes to people with learning disabilities in our area.

I am very proud that I was able to set up and help run a training team of people with learning disabilities who train for the NVQ and the Learning Disability Award Framework. We also talk to care staff to make sure that people are made aware of people with learning disabilities.

Q What makes you angry?

A When people don't listen to us, (people with learning disabilities). We are the experts and we need to be listened to. Even if people cannot speak they have their own language and ways of communicating through their advocates or through someone they can trust. Everybody has a voice and they should be heard.

It makes me very angry that the Government has not listened to people from black and ethnic minorities and people with high support needs who need a lot more support and help.

I get angry when consultation papers come out and we have such a short time to reply to them. We need time to be able to answer the surveys. They need to be published in easy read format to help people read them. People with learning disabilities find it easier to understand documents that are produced in easy read format, using symbols and pictures.

Q Have you a message for the readers of Community Connecting magazine?

A Yes I have. My message is that people should listen to people with learning disabilities, we are the experts and we should be asked for our opinions. I think that Community Connecting should talk to other people with learning disabilities to find out what they think not just me because of my new job.

Nicola went on to say:

“I would also like to thank you readers for reading this article about me and my new job. I feel very honoured and thrilled that I got the job, and I know it will be a tough road ahead. I know that I won't be able to reach everyone, but hopefully through your readers we can spread the word about what I am going to do.

Later in the year I hope that when I am more settled in my job I will be able to give you an update about my progress on the three main priorities for my job, which are:

- Closure of hospital campuses - making sure that people have better lives, not living as patients of the NHS, but living independently and having the support they need.

Most people we know who are living this way don't need medical treatment. They should not be living in places where they are classed as patients where they have no rights or a chance to go out and enjoy themselves, but they are stuck inside and are given drugs to "keep them calm". That is why people have challenging behaviour! We need to stop it. We need a new generation of people who are given the chance to have better lives and better support and the correct medical treatment. They must be classed as citizens, not patients.

We need to make sure that hospital campuses are closed down properly so that people do not have to move away from friends and family, and have a right to choose who they live with.

- Relationships with the self-advocacy movement - making sure that advocacy is spread round the whole country and that the Government gives more money to advocacy groups. Everyone who needs an advocate should have one. Advocacy groups help to make people with learning disabilities have a voice about their lives, benefits, working, where they live and their health.
- Family carers to make sure that carers have more rights, and that they have support too!

Lots of people wouldn't be here today without the help of their carers. Carers have fought for people with learning disabilities in the past, now we need to look after our carers.

Thank you for listening to me".

Contact: info@communityconnecting.co.uk

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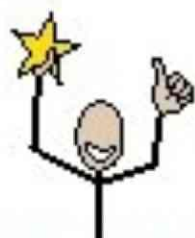
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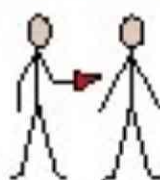
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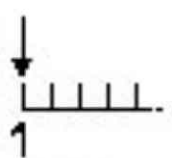
Nicola Smith: Tsar for Learning Disabilities



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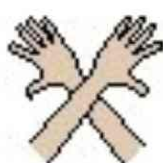
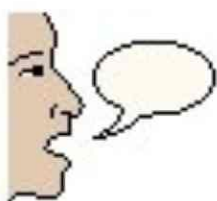
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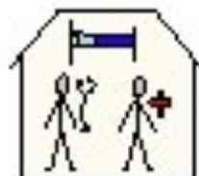
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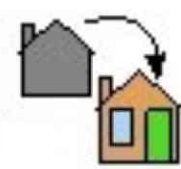
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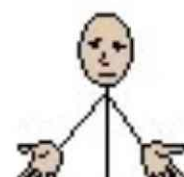
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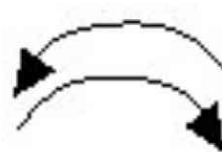
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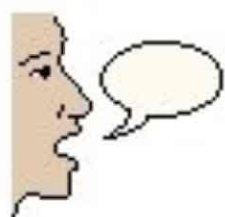
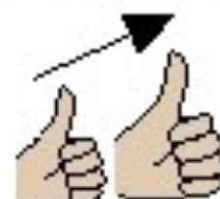
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needs to



change and improve?



More listening,



leisure,



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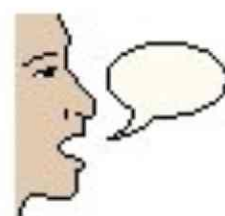
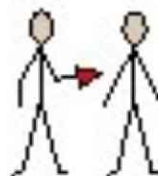
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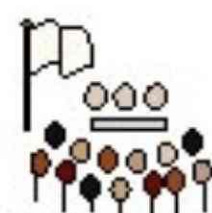
What sort



of jobs do you have to do?



I will talk to the Government



and advocacy groups

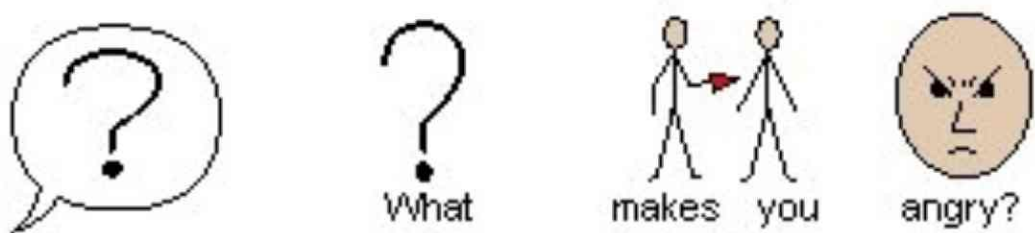




What makes you proud?



My NVQ Award, Advocacy Group and Training Team



What makes you angry?



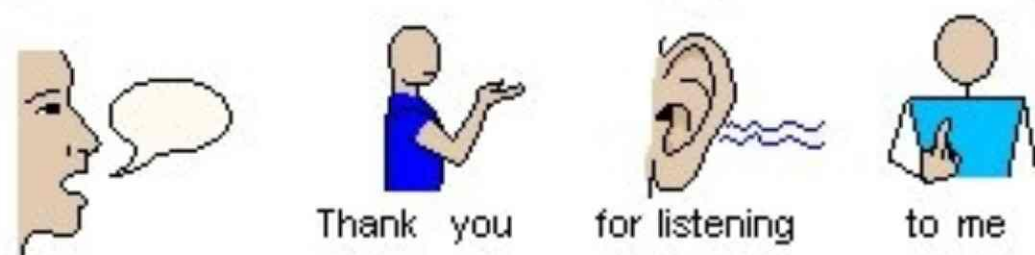
People who make their documents difficult to read



Do you have a message for our readers?



Yes. Listen to people with Learning Disabilities



Thank you for listening to me

The name 'Small Sparks' is borrowed from the community development project run by the City of Seattle Department of Neighborhoods, 'Involve all Neighbors' Project.

How Small Sparks works

It is simple. An organization (like a Local Authority) offers grants of up to £250 to individuals who have an idea for a project to improve local community life. People have to match the £250. They can do this in funding (perhaps as a donation from a local business), in materials, or volunteer labour. Most people use their time and labour.

If, for example, someone wants to paint a mural and contributes 20 hours labour (valued @ £8 an hour) and a £50 donation of paint from a local shop, this adds up to £210. Small Sparks matches this with another £210.

Small Sparks in Seattle

One of the many stories from Seattle is about Mark, a young disabled man. His mother realised that he did not have many connections in the neighbourhood. So they dreamed up a project which would be useful for the community, one in which Mark could be the leader. They used the \$250 for their project called 'Walking the Wagon'.

They bought a trolley cart and set off to pull it around the neighbourhood. They knocked on doors and asked for magazines people didn't want any more. Then they would ask if people wanted magazines from the cart. People flipped through the magazines and would ask 'who likes cycling round here (or trains, or cooking)?' Mark would tell them who gave those magazines. He became known as the guy who put people in touch with each other. Soon everyone wanted to pull the cart. Walking the Wagon became a feature of the neighbourhood and Mark was seen as a community leader.

Small Sparks in England

'In Control' liked this idea and wanted to try it in England. 'In Control' is an organisation that is creating a new system of social care; one in which disabled people have control over their funding and their support. Because most disabled people want the same things as anyone else, many use their support money to help them get an ordinary life in the community.

'In Control' thought Small Sparks would be a simple way of helping people to get involved in their neighbourhood and

make new friends. So £10,000 was offered in grants. Redcar, South Gloucestershire, Wigan and West Sussex Local Authorities each gave out 10 grants of £250 to 40 projects in all.

The grants were advertised. People who wanted to be 'Small Sparkers' had to:

- Come up with a good community building idea perhaps with a bit of help.
- Give the project a catchy name.
- Involve new people in the neighbourhood not just other disabled people.
- Finish the project in 8 weeks.
- Make a record in photos or video and a brief story.
- Tell the story of their project at a Small Sparks celebration.

'In Control' waited to see what would happen. Perhaps this would work in America but not in England.

But stories of what Small Sparkers had done started to come in. They were good. With just £250 and a good idea, people had achieved remarkable things:

In Wigan, Joseph Tomlinson, with the support of his mum and dad, used the money to print a flyer advertising a sponsored cycle ride. 200 people came. £7,000 was raised for Wigan Scope. Joe became well known in the neighbourhood for his part in the ride. His mother, Caroline, says 'lots of people knew Joseph before, but a lot more people know him now'. There was an important spin-off. Some weeks later Caroline got a phone call. The caller said: 'I was on the cycle ride; I've just seen your Joe with people I don't recognise. Is that ok?' This kind of neighbourly vigilance watching out for each other answers the question raised by those people who worry the community is a dangerous place for disabled people. When people are known in their neighbourhood, watched out for, missed when they are not there, this is the kind of real care that communities can



Hand over the cash, then people do the rest.

provide. It may be a better safeguard than some of the regulations and inspections that try to keep people safe in services.

In Redcar people from a day centre have an allotment. Just being in an ordinary place in the community had not automatically meant they were well connected with other allotment-holders. They received a Small Sparks grant. They spent it on a barbecue; a gazebo, food and drink and they invited the other allotment-holders to the barbecue. People came and there were probably lively conversations about who had the biggest tomatoes. The Small Sparkers now have plans to raise some more money to put up a fixed shelter where everyone can gather when it rains.

In West Sussex some people had found it difficult to open a bank account. They decided to find out their rights and tell others. They used the Small Sparks money to buy display materials and got the agreement of a local bank to set up a stall and explain 'Easy steps to banking'.

Another project in West Sussex was similar to one in South Gloucestershire. Both were about children and reached out to other people in the neighbourhood who share the Small Sparkers' interest in children's issues. A young woman in West Sussex liked the local toy library and offered to help the library celebrate 30 years of its' work. They worked together to arrange a playday; a lively event with a music bus, arts and crafts and other activities. The people from the toy library came to the celebration and were full of praise. They immediately started to plan their next event together. Sonia

Redcar Garden
Volunteers



Walking the wagon, Seattle

Nethercott in South Gloucestershire said: 'I want people to talk about what more can be done for 'under 5's' in this area.' She organised a sports day for under-fives at the local community centre. Lots of people came. Sonia said that she found it very stressful to organise but she is proud of her achievement.

In these projects disabled people worked in alliance with local people around a shared interest. Carolyn Carlson, the person who started the Small Sparks idea in Seattle, says that this approach holds the greatest promise of people making lasting relationships.

Small Sparks has proved so successful that 'In Control' is supporting nearly 20 more Local Authorities to start projects like these.

Any organisation that wants to help people to get connected in their communities can do Small Sparks. You don't have to be a Local Authority. You can still take part in 'In Control's' Small Sparks network.

If you want to get started right now you can steal an idea from Redcar the Community Chocolate Challenge. It remained just an idea there. Buy £250's worth of chocolate. Put it on a table and invite everyone in the neighbourhood to come round and eat it. You'd have to go, wouldn't you?

To take part in 'In Control's' Small Sparks network, contact Carl Poll: carlpoll@ukonline.co.uk

The benefits of Small Sparks can be enormous. Disabled people:

- create small projects which are of direct benefit to other ordinary members of the neighbourhood
- are valued for their contribution to the neighbourhood and may be seen as community leaders rather than recipients of services
- discover connections to others and develop meaningful relationships
- create their own meaningful activities outside of organised programmes
- have an increased sense of self-worth as important members of the community
- stimulate spin-off activities.

Carl Poll is a member of 'In Control' core team. He has the lead for community development and publications at In Control.

What do the Houses of Parliament, Sainsbury's, Southbank University, The Unicorn Theatre and the Old Post Office Bakery have in common?

People who attended an Employers' Breakfast hosted recently by Toucan Employment will know the answer, as all five organisations spoke positively about their experiences of employing people with learning difficulties.

Since 1989 Toucan Employment has been working with people with learning difficulties in Southwark. More than 300 people have been supported into a wide variety of jobs, with employers as diverse as the Ministry of Defence, The Royal Festival Hall and Urban Outfitters.

Toucan supports around 70 people a year in supported employment. Targets are very important to the organisation as the Managing Director, Ray Whittaker, explains: "working for an Employment project, it is vital that we can show that we get results." Toucan has many service users who have been in jobs for many years but the project also focuses on numerous potential jobseekers who have little or no experience of work.

There seem to be more and more projects focusing on Employment training etc - some of them have been in existence for years and never seem to achieve anything other than voluntary work. What makes Toucan different is its track record and success in finding people paid employment.

It can be really inspiring to see how much having a job means to a person. Sangeeta, one of Toucan's senior Employment workers said "you feel really good when you see someone in work and know that the job you do literally has the power to change somebody's life. The job can be quite difficult at first; you have to get used to employers who don't want to employ our service users, but when you make a positive contact and see somebody in a job they love it makes it all worthwhile". Sangeeta currently co-ordinates a highly successful project working with young people. Employers such as London Transport, The YMCA, Kings College and ASDA have all employed young people from the project.

Pippa, another senior worker, has managed to secure many jobs for people over the years including four within the Houses of Parliament. "It's good that we have an employer like the House of Commons that has shown such a positive attitude. It means a lot to those four people but also helps us to show other employers that it is not only a good thing to do but can work very successfully even in the most surprising places," says Pippa.

Toucan has always supported people in a wide variety of jobs. People are not just pushed into any job that is available but are

individually job-matched. This means that people have had the opportunity to work as Grooms for the Household Cavalry or in The Hayward Gallery as well as Supermarkets, Cleaning and Gardening work.

The Project focuses on the ability and interests of people. It's very much a 'can-do' philosophy. As Ray, the manager, says, "it is important that people are given the opportunity to succeed in employment. It doesn't always work out as well as possible, but it's important that people are given opportunities."

One successful project run by Toucan is the Van Gogh Café - a popular Café on the North end of the Brixton Road. The Café is very different from many other projects run by services for people with learning disabilities. From the outset the goal was to be as commercially successful as possible. It was always intended to be a very visible project, "we wanted the Café to provide real jobs and help to make social inclusion a reality".

Having a job means so much to people with learning disabilities. Just about every survey ever taken of peoples' wishes shows that employment is something that most people want. Despite that, funding for organisations such as Toucan makes up only a tiny percentage of spend on social services.

Employment is an immensely positive issue for people with learning disabilities. It is the best way of fostering social inclusion and involvement of people within their communities. When you consider how much is spent on social care services, one could question how little is spent to support people with learning disabilities to achieve employment.

"Services should not just provide care but also opportunities to Earn and Learn," as Ray makes clear. "It is imperative that issues of user involvement and consultation include people with learning disabilities in a meaningful way, and that has to include their role as paid employees".

One of Toucan's users works for Advocacy Partners. It is good to see people in full time jobs with Advocacy projects. More forward-looking organisations appear to be recognising the ability of people to influence their own services.

That people with learning disabilities want the chance to contribute to society should go without saying, but still far too few are in paid work. In Southwark, Toucan has a proud record of helping people find and retain work. The support people get can be quite intensive and is individualised not only for the needs of the employee but also for the employer. Toucan has

been fortunate that its Local Authority has, for some time, recognised the value of its work and has been able to build on this and enlist the support of other funders.

Funding Employment projects is extremely important, as is the need for these projects to have real targets for the numbers of people placed in work. Paid employment changes peoples lives, it gives them increased independence and confidence. People should have the right not just to receive care and support when they need it, but also the chance and support to contribute.

Service users' views are a really positive way of looking at the success of Toucan. People spoke passionately at the Employers' breakfast about their jobs in the Houses of Parliament, at the Van Gogh Café and the Unicorn Theatre. One young man had just secured employment as a play worker and made clear how pleased and proud he was.

Jeanette who works at the Café told everyone just how much having a job meant to her. "I love this job. When I'm at home I'm looking at walls 24/7. People should do more to give people with disabilities jobs."

Other service users such as Bill, who works in a Doctors' surgery three days a week, are equally enthusiastic about Toucan. He had been attending a day centre four days a week for years but now has a very different life. One service user, Anthony, was supported into a job at Sainsbury's and ended up getting his dad a job in the same store!

Toucan also recognises that often people want to move on from work. Brian moved on from his job as a hospital porter at St Thomas's to work as a road-sweeper for Southwark council. Nanette previously worked at Gap but the prospect of working at the House of Commons was too good to turn down and she moved into her new job in 2004! Kenny was supported to get a new job with leisure services when the Velodrome he worked at shut down.

Sainsburys has provided a good source of jobs for Toucan's clients. Michelle the Personnel Officer at Sainsburys' New Cross store explained, "Toucan provided excellent support to

both us and Hassan who was on work experience, we were really happy with him and he is now doing really well as a paid employee". Matt from the House of Commons said "At first we were unsure of how things would work with Toucan, but it went really well with Brendan (the first person). We now employ 4 people through Toucan and will hopefully be able to employ more people, its been really positive for all of us and its important that more people support the work of an organisation like Toucan".

Ray believes that Toucan's success is based on:

- Toucan's committed and enthusiastic staff team
- Building strong relationship with users and employers
- Job Matching: drawing on peoples' interests and abilities
- Individualised Job Support: helping people to maximise their independence at a pace they can cope with.
- Ongoing support for employee and employer as necessary

Toucan adapts well to change, but one of the biggest obstacles it faces is that other organisations don't refer as many people to Toucan as it could support. This may be, in part, due to a lack of services' understanding of the successes of paid employment, but also Toucan needs to learn to celebrate its' success and find a way of raising its profile.

Contact: info@communityconnecting.co.uk

Brendan and Frede Nixon



Anthony Pedro



Thanh Hoong



Liz Crawford



Anthony Witherington

A Guide to Person Centred Planning

Most service providers, if asked, would proudly declare that they are 'doing person-centred planning'. And most would believe it.

by Simon Duffy



But how many, when asked to demonstrate this would pull out glossy, colourful 'Plans' that have little to do with a person's dreams and aspirations and do little to show what real changes have happened in someone's life.

Simon Duffy, in his book 'Keys to Citizenship' defines the 'keys' to people achieving true citizenship as 'having control, direction, money, a home, support and a community life'.

To be able to make decisions is the first step, and some people may need some help with that. But in life we don't just need to be able to decide things we also need a sense of *what* we are trying to achieve, our direction, a plan. So we might say that the first step to citizenship is to have control over our own life, but the second step is to give that life direction.

It is important that everyone's life has a purpose, a personal direction. Purpose is not about having every step of your life planned out or about achieving some final goal. Purpose is about finding your own path; a path that feels right to you and developing a lifestyle which offers you satisfaction and personal

fulfilment. Having a purpose is not necessarily easy and it is quite common for any one of us to find that our life has gone adrift; we find ourselves unhappy or trapped, (may be in a relationship or in a job or in a service), but afraid to change or uncertain what to change towards. One word that is commonly used for the process of giving your life direction is to plan. There are lots of good reasons why planning is important in life:

Planning helps us change things we can all get stuck in a rut. To get out of the rut we need to work out what we would like to do instead that is the same as having a plan.

Planning helps us feel more confident we can feel worried, frustrated or angry when we don't know what we want. Planning can help us work out what we want to change and how to do it.

Planning helps you work with others it is important that other people know the plan so that they can change what they do. Plans help everyone act differently.

Planning makes things real when we talk about our hopes and dreams we can begin to plan how we may achieve these.

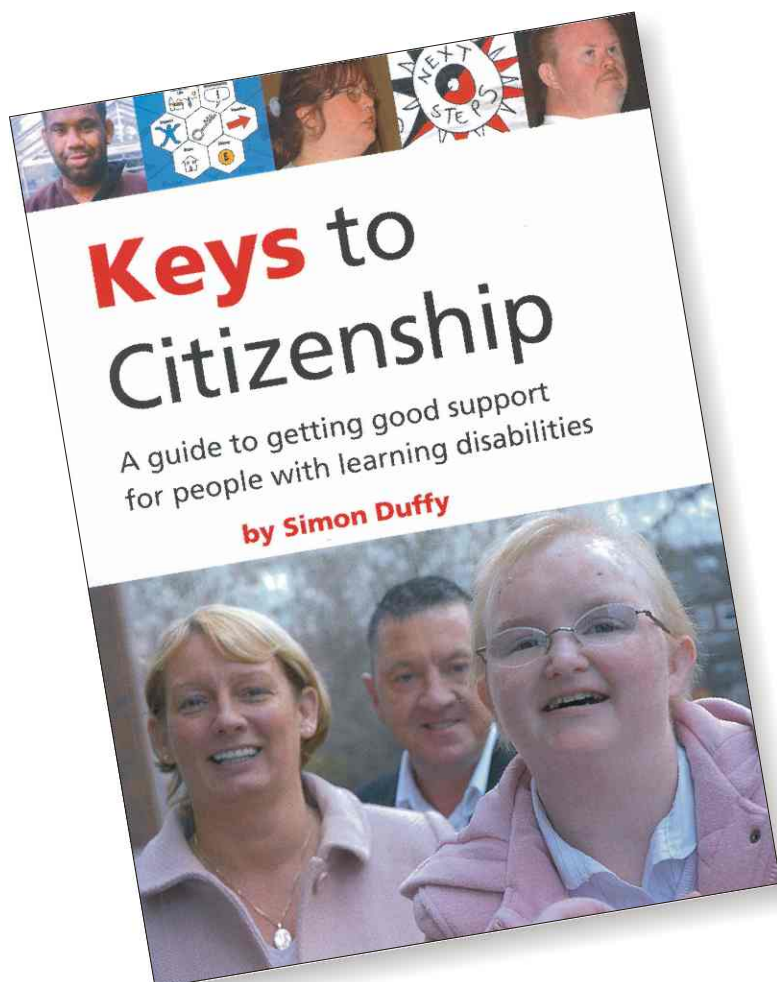
Person Centred Planning is about working with someone to find out what they want to do with their life and working out how to make it happen. It is very different from a 'care plan' or 'assessment' that looks at what a person cannot do. These focus on the 'service' a person needs, instead of helping people get a life.

Real person-centred planning:

- Focuses on the person's gifts and tries to use them.
- Starts by focusing upon what is most pressing for the individual.
- Gives most emphasis to the voice of the person themselves and to those who love them.
- Helps people use of their networks and their community.
- Lets friends and family be much more involved.
- Doesn't care about sticking to rules, it is creative and flexible.
- Is organised to suit to the person and their community.
- Puts the person in charge of who's there and what happens.

So Person Centred Planning is basically not a fancy new way of planning. It is about a fundamental shift from services planning for people to people planning for themselves.

However, to make this shift towards being Person Centred is difficult. For it is not usually a negative attitude or ignorance that stops people from looking at things from the perspective



of the person; it is a whole range factors that inhibit and limit our imagination:

- Life is not easy - we can feel swamped with problems and lose track.
- Support is powerful - it's easy to stop seeing the people we help as whole people.
- We all make too many assumptions - human beings work from stereotypes.

It's for these reasons that people began to develop Person Centred Planning, a way of planning that helps you focus on the real person and set a direction that is true.

What is Person Centred Planning?

At the heart of Person Centred Planning is the belief that every single individual has their own life to lead, a life that is right for them. Sometimes it is difficult to work out the best thing to do and sometimes we need people to help us work out the best thing to do. Person Centred Planning is the process of helping someone work out the right thing to do, for him or herself. At its simplest it involves:

- Understanding yourself
- Setting your own goals
- Working towards those goals

1. Self-understanding

If your plan is really going to be your plan then it needs to be a plan that is based upon some understanding of the unique individual who you are. There are many different ways of understanding who you are and so there are many questions you can use to uncover who you really are. Here are just a few:

- What works for me? What doesn't work for me?
- What are my everyday positive rituals and routines? For instance, how do I like to get up in the morning? How do I like to spend my Saturdays?
- What would my ideal holiday be like?
- What are my dreams and hopes for the future?
- What are my nightmares and fears?

- What does a good day for me look like? What does a bad day look like?
- What are my gifts and skills?
- What makes me feel safe?
- What are my strengths and needs?
- What would I do if I won the Lottery?
- What do people like about me?
- What do people respect about me?
- What do I want to achieve in the next 5 years?
- What would an ideal week look like for me?
- What is my life story so far?
- What would I like people to say about me at my funeral?

All these questions, and many more, share the purpose of trying to help us reflect on our unique identity or purpose. Some are more mundane than others. Some are grand and ambitious. But all of them take for granted that we each have our own unique identity, one that may even be lost or hidden, but an identity that is truly our own

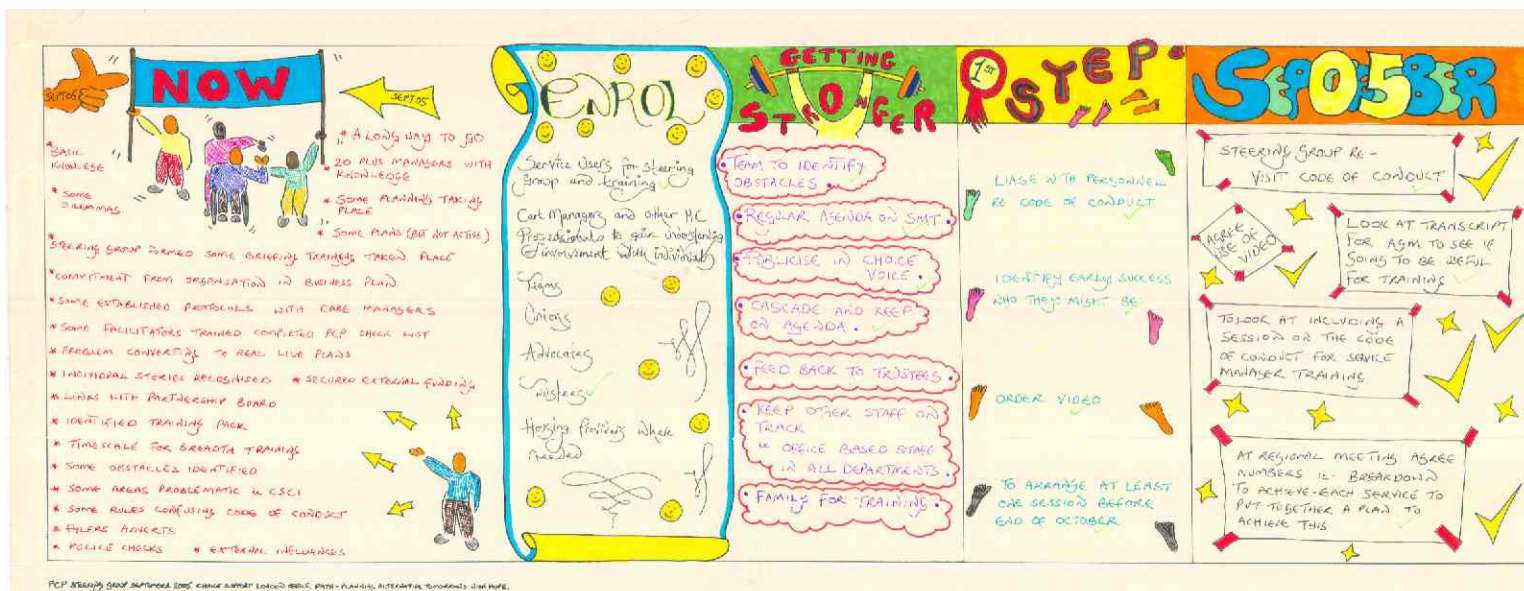
2. Setting goals

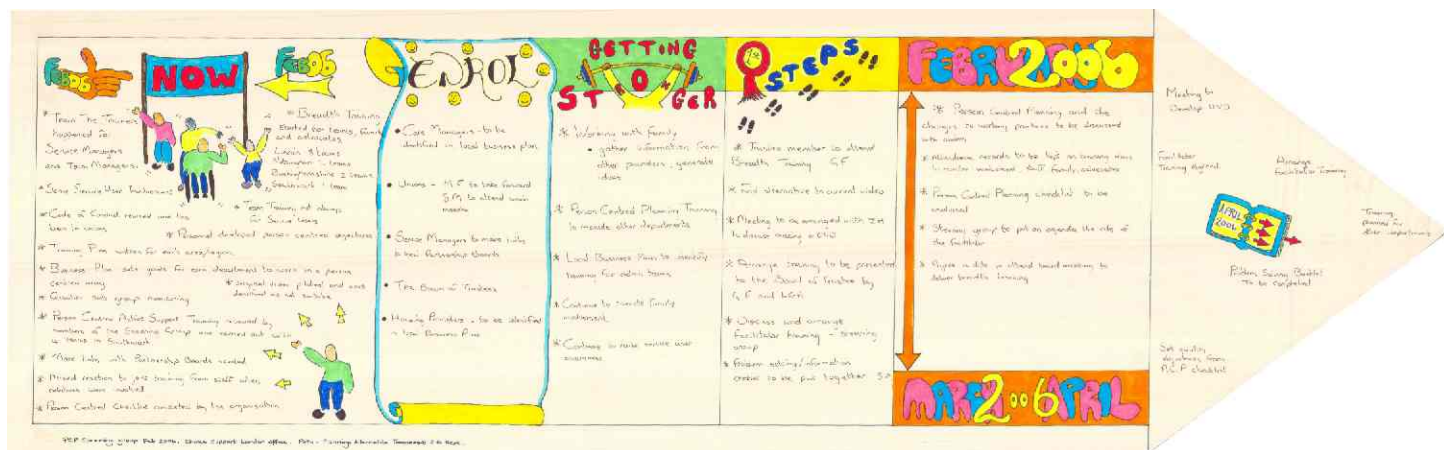
Once you have some sense of who you are then you are able to begin the process of finding a direction for yourself a plan or a goal for your future. Nobody can tell you what goals you should have. But there are some things that tend to be very important and they are set out in the following list:

- To make everyday choices
- To have people treat me with respect
- To take part in everyday activities
- To have friendships and relationships
- To be part of my local community
- To get the chance to work
- To take part in important decisions about my life
- To have people listen to my family's views
- To be safe from harassment and abuse
- To get help to stay healthy

3. Making the plan happen

Planning is more than just defining your goals. Planning should





- You have special routines or rituals that you want others to know so they can support you better.
- It's difficult to let people know what is important to you by speech alone.
- There is confusion about how best to keep you safe or healthy.

Ideally you would find someone trained in Essential Lifestyle Planning to help you develop your Essential Lifestyle Plan. The planner can meet several people at once or can hold interviews with key people in your life. At best it will take one day of meetings or several days of interviews to gather the necessary information. It will also take up to one whole day to write down the information and organise it. This information is not even a plan yet, although it should contain guidance to your supporters on how best to support you. The planning begins once the information is gathered and how best it is done will depend upon the issues raised.

PFPP Personal Futures Planning

Personal Futures Planning was developed by Beth Mount. It is a flexible set of questions and graphical maps that can be used to build up a sense of who you are and how you would like to live. Personal Futures Planning is much less structured than the other approaches and offers a range of questions or approaches suitable for different problems. It is a really good thing to use when:

- You want to get more involved in your local community.
- You want to improve your network of friends and family.
- You want to plan for something really specific, like moving house or leaving school.

There are a number of books you can use to learn more about Personal Futures Planning and some people have been trained to use it. Personal Futures Planning can be done in half an hour or it can take much longer, depending on what you want to use it to explore. Although it is less well defined than the other tools its great strength is its flexibility and its attention to the opportunities that are created by life and our relationships with others.

Making Your Own Plan

These different Person Centred Planning Tools are all excellent. But you may find that there are better ways of asking the questions you want to ask yourself or involving

others. Some people have used their own special ways of getting a plan. Here are just a few examples:

- Planning and playing bowls at the same time.
- Turning the plan into play-acting.
- Making a game out of the plan.
- Interviewing people instead of having meetings.

There are no rules about what process to use. Just think about what you want to find out and then ask yourself what might be a good way of finding the answer.

Who can help you plan?

If you feel that you or someone you care about would benefit from having a Person Centred Plan, but you are daunted by the idea of doing it there are a number of things you can do:

- **Get training** - sign up for training courses in Person Centred Planning. There are many available across the country, many of them are free or highly subsidised for people with learning difficulties and their families
- **Read the books** - There are many more detailed accounts of how to do Person Centred Planning than are available in this book. Most of the important books are listed in the bibliography.
- **Meet up with others** - Possibly the most important way of learning about Person Centred Planning is to find ways of meeting up with other people who are trying to do the same thing. From them you can gain confidence, practical support and ideas about how to do it.
- **Support Brokers** - Occasionally you might find that there are service brokers or independent advocates who are skilled in Person Centred Planning. This is possibly the ideal kind of help, as service brokers are independent of both the local authority and service provision. Unfortunately there are only a few service brokers presently available.

The most important thing is to make sure you **just do it**.

Don't be overawed by all the different planning tools, questions and ideas about the process. Start by planning, get together with some people that you care about and who care about you and think about what you want to do. If you are doing this on behalf of someone who doesn't communicate with words then try to think about what they would say. Then write down your plan just having a written plan can give you immense authority when dealing with others.

What is a Support Plan?

Person Centred Planning has been one of the key ideas that have helped people see that all disabled people, if we organise things properly, really can be in control of their own lives. In the future people will control the money for their own services then it won't be services that plan what they are going to do to people, instead people will tell services what help they need to live their own life. In the future local authorities will stop doing Care Plans for people; instead they will ask people to tell them about their Support Plan.

The idea of Support Plan is important and more information can be found about Support Planning at www.in-control.org.uk but several local authorities are already using the following framework. A good support plan needs to answer the following questions:

1. Who are you?

The plan must be about you, the real you. Somebody who loves you or cares about you would be able to recognise that this plan was about you.

2. What are your plans for the future?

The plan must set out real and measurable things that will have happened in the future so that it is possible to see whether the plan is working or not.

3. What support will you need to do what you plan?

The plan must say what kind of support you are going to use to do what you want to do.

4. How will you stay healthy and safe?

The plan must say how you will make sure that you are not going to be in any great risk of coming to harm and also how you will keep other people safe from harm.

5. How will you stay in control of your own life?

The plan must say how you will stay in control of your own life. This means looking at what decisions you will make and where other people make decisions for you how they make sure that you are involved and that you would agree to them.

6. How will your support be managed?

The plan must explain how any support you pay for is going to be organised. This means saying who is going to manage it and how you will sort out the payment of salaries or other necessary practical arrangements.

7. What will your support cost?

The plan must set out what the support service will cost for a year and what money will be needed for the following two years. This must be within an amount agreed by North Lanarkshire Council.

Why is Person Centred Planning useful?

In conclusion it is worth stating what Person Centred Planning can achieve, but also clarifying its limits, what it won't achieve by itself.

1. It is positive

Person Centred Planning is a positive experience, one that can provide you with a chance to think about your strengths and interests and then build on these.

2. It is inclusive

Person Centred Planning is designed to include others and to work in a non-professional, non-judgemental way.

3. It is realistic

When Person Centred Planning is done well it is highly realistic. Although it may involve asking you to put reality to one-side for a moment, as part of the process of dreaming, it has to return to reality.

4. It is respectful

Good planning is respectful. It is done at your pace, where you want and it involves people who you trust and value.

5. It is powerful

Good planning is powerful. It draws together different people, creates a shared image of the future and it gives people the permission and clarity they need to head towards that goal. It doesn't always lead exactly where one intends. New learning happens, people change their minds, but it helps people take control of their lives in a powerful alliance with others.

Real Person Centred Planning creates a sense of purpose to life and, for the people you meet, it helps them understand the meaning of your life. This is what we look for in each other and it provides the second key to citizenship. For when we recognise that someone has their own purpose, their own reason for being here, then we can recognise that they too have their own life to lead, one that is worthy of respect.

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Patrick's Story

Person Centred Planning helped Patrick escape from the challenging behaviour unit and move into his own home, with support from family, friends and with paid staff.

First a version of Essential Lifestyle Planning was used to build a detailed picture of Patrick and how best to support him, how to understand his autism and how to help him to not panic and to harm others. Then Patrick and his family were helped to do some Personal Futures Planning and to design a 'dream home' for Patrick.

Amazing as it may seem Patrick now lives in exactly the kind of house that those who love him imagined for him, it is appropriate for his visual impairment and has extra bedrooms so that his family can stay over and he can live-in supporters. Now Patrick's team work to a personalised Support Plan that helps them support Patrick to enjoy his new life, far from the hospital walls.

**Paradigm and
'Community Connecting'
magazine host the UK
launch of Assets Based
Community Development**



'Community Matters' was held at the Thistle Hotel in London on 24th May 2006 to coincide with the first anniversary of the launch of **Community Connecting** magazine. The conference chairs were Patrick Kenny and Steven Rose. Patrick is a very funny, sincere and perspicacious man. He launched the conference with his unique style of chairmanship that would not allow any member of the audience to remain uninvolved or uninspired. Steven who referred to himself as 'the straight man of this double act', followed with further inspirational observations. He spoke of 'Community Building' as being one of the four cornerstones of support, along with Person-Centred approaches, individualised funding and strong advocacy. This theme was reinforced throughout the day.

Nan Carle, from Tucson Arizona, who spent 20 years working with people with learning difficulties in the UK, intrigued us with a photographic essay, a pictorial walk through her own local community. Nan is remembered by many for her work with VIA (then CMH), as a founder of Choice Support (then Southwark Consortium) and as the Director of Learning Difficulty services in Lewisham & North Southwark in the 1980s. She told us that Community Building helps us "create places where citizens can act like people who care about each other". Nan proceeded to give the first national presentation of Assets Based Community Development (ABCD) as a tool for 'Community Building'.* Nan also spoke of recent challenges she has faced in working with some families who are seeking to establish a small intentional community; whilst she has spent her entire working life breaking down institutions. This issue arose in discussion throughout the conference and the most important element that emerged was the real choice of the

person with support needs and their family and their equal and valued role in their community alongside others.

Patrick then led an interactive session that asked the audience to consider: what were their dreams for their communities, how could stronger relationships be built within these communities and what could services do to assist people to be part of their communities. There was lengthy debate and discussion and in feedback a number of interesting and intuitive comments were made, which Patrick accepted gratefully, describing them as 'vitamins for the soul'.

Suzanne McStravick, Paradigm Consultant, talked about 'Building communities from within services'. She spoke of 'serviceland' that may offer a safe and secure environment, but also offers a life that is very isolated, devalued, disempowered and very restricted. She challenged service providers to "open your eyes and think about what people can do; their values, gifts and capacities." She said that Service providers should be creating the 'right support for people to get a life'. Person centred approaches are essential but 'we should also realise that sharing someone's dream is both a privilege and a responsibility and helping people to move on is not just about 'changing an address, but about changing a life.' Encourage people who are supporting others to be brave to have the courage to take the first step.

Just before lunch Carl Poll talked to us about two projects in which he was involved. One was 'Small Sparks' a concept rather than a project, in which a small investment is made, that enables an event to take place within a local community (see Small Sparks article on page 09). This builds and strengthens relationships within that community and is clearly one area in which people with disabilities can connect with others and make an equal contribution within their

communities. Carl also told us about 'Manavodeya' (meaning human awakening), a project in the poor villages around Lucknow, India. This project is based on putting in the support necessary to enable people to help themselves. It is around a values-based practice that believes that social change starts with personal change; the whole idea of collective change has to be built upon trust. Only from a position of humility can we move from a position of 'knowing things' to 'learning things' and this enables us to 'hand over the stick'. The message was loud and clear 'people need to live the values rather than talk about them endlessly'.

After lunch we were treated to a performance by 'Streets Alive' a theatre company that works with young and homeless people. Everything 'Streetwise' does is about supporting young people to reclaim their lives. These amazing young people put on a thought-provoking and challenging play around bullying and street crime. They then introduced Forum Theatre in which members of the audience were invited to take part in the play and change the actions of a character, thus potentially changing the outcome of the play. There is no doubt that one member of the audience, Boo Dandy, was a natural actor who totally transformed the ending of the play well done Boo!

Martin Brennan explained 'Time Banks' how people could spend time helping others but also claim back time in support in a way that would be useful to them. This seemed to be the ultimate in volunteering but more than that a way that people

within a community could have a valued reciprocal relationship. Anyone could play a valued role within such an exchange of time, gifts and values. This turns around the current service model that focuses on what support needs a person has, and recognises that most of the people we support have an amazing array of gifts that we just don't tap into.

In closing the conference, Nan Carle said that 'ABCD offers us a framework to talk together about the things to which we do not know the answers on our own.' In his closing remarks Steven Rose reiterated his comments from the editorial of issue 5 of **Community Connecting** "I confidently predict that in years to come we will look back and see that Nan's promotion of ABCB in the UK will have had an equal influence in shaping services as Normalisation and John O'Brien's ideas did at the end of the last Century".

A superb and inspiring conference. One expects nothing less from a Paradigm event.

*** Nan's ideas on Assets Based Community Development have been featured in issues 1 - 5 of Community Connecting. To order back issues of all five copies for just £10 (including P&P) send a cheque to Community Connecting magazine Suite 63, 151 High Street, Southampton, SO14 2BT quoting offer code: CC06ABCD**

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Patrick Kenny, Nan Carle and Steven Rose

Person Centred Thinking: The Doughnut Principle

I was recently fortunate enough to be invited by the South & East Belfast Trust to attend some training delivered by Julie Allen, Helen Sanderson Associates, and Bronagh Hillen, South & East Belfast Trust, on Person Centred Thinking.

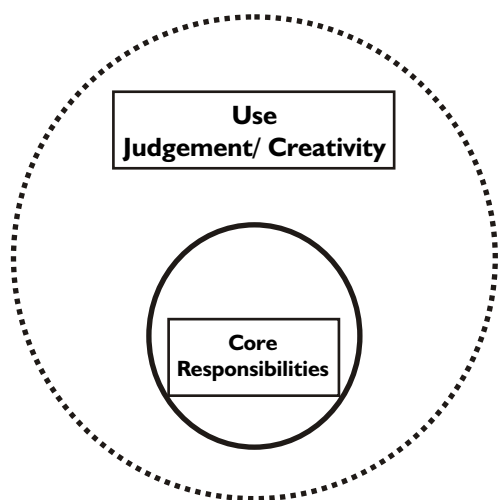


by Kevin Barnes

Here I was introduced to the Doughnut Principle as described by management guru Charles Handy. In Handy's 'Doughnut' the centre, far from being empty, is filled in. If you draw it you will see something like a fried egg, a small solid centre surrounded by a white space bounded by a roughly circled line. I have to say I have previously been skeptical of gurus.

In the Doughnut management theory the solid middle represents the essential elements of the job, things that have to be done no matter what. But the responsibilities don't end there. The white space is the opportunity for initiative and creativity, for going beyond, for adding extra value, for getting more out of less. There is, however, a boundary, an official limit to discretion, and the line beyond which one should not go.

**Not Our "Paid" Responsibility
(the Domain of friends)**



Person-Centred Thinking, developed by Michael Smull and Helen Sanderson, developed this idea for staff who have a support role with people with a disability. Increasingly staff are asked to simultaneously support choice, build relationships and assure health and safety. People who are 'naturals' in this role will easily get the balance right. However, many others can get caught up with either the first or last message as was stated on the day: "happy and

dead" is not an option but equally neither is "safe and miserable." What is important is that this balance is defined with each individual we support.

Michael W Smull
(From Charles Handy)

The Doughnut principle as adapted by Michael Smull for supporting people with disabilities suggests that there are three areas of responsibility that can be defined with each person we support. At the centre of the doughnut are the core responsibilities: those things that we need staff to do without fail. These core responsibilities should be a mix of health and safety issues and those things that are important to the person. The middle white space is the area where we should encourage, expect and support staff to use their judgment and creativity. These are areas where people are allowed to try new ideas and not be held to blame if the ideas do not work out. Outside of the doughnut are those areas that are not our responsibility or to put it another way none of our business.

At the training I attended it was explained that the boundary between core responsibilities and areas where people can use their judgement should be clear and well defined. If someone requires a particular medical intervention or if a particular routine is important to a person this is not in the area of creativity but is part of our core responsibilities. The outer boundary between judgement and 'none of our business' is deliberately kept blurred. For example: how someone dresses might be none of our business on a day-to-day basis, but could fall into the area of use judgement and creativity when they wish to go out to a nightclub.

Management gurus like Charles Handy have never been essential reading material for me. But in future I will try not to be so blinkered and be open to gaining knowledge from other organisational learning. However, another leading thinker of the 21st century, Homer J Simpson, has already highlighted the potential benefits of doughnuts when stating "doughnuts, is there nothing that they cannot do?" mmmm doughnuts.

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Employment Opportunities Aim For Broadsheet Recognition

Wrexham Social Services Job & Employment Opportunities Service hopes to win a prestigious reference by being recognised in the Guardian Newspapers "Public Service Award" for 2006.

Team Manager Cheryl Biggs is attempting to illustrate the developing range of options; many of which were initiated during the early stages of the 'All Wales Strategy' (1983).

Changing demands and pressures have seen rationalisation in some areas and broadening or enhancements to match changing business and service delivery environments over recent years, as legislation and maturity of service have altered.

Day Services & Work Opportunity Services in the past were separated into need specific services, but bringing Mental Health, Learning Disability & Sensory / Physical Disabilities services into one facility's best practice increases the likelihood of meeting individual aspirations.

The integrated service has approximately 60 staff supporting 280 adult users to develop "work" based and associated social skills, to boost confidence; working within the Social Enterprise Model.

Range Of Services

Two traditional day centres for people with Learning Disability & Mental Health needs, have been re-badged as 'Resource Centres' with the aim of meeting the needs of a greater number of people with a wider range of support needs.

The Cunliffe Centre offers;

- An "outreach" link from a local

Further Education College, leading to nationally recognised qualifications.

- A number of service user consultation groups and fora, facilitated to give users a real voice in the development and delivery of services.
- "Actability Disability Awareness Workshops", wherein Users are involved in attempting to change attitudes to disability.
- A number of small businesses e.g. desk top publishing & garden furniture workshop.

Haulfan Centre offers;

- Art & Craft Sessions.
- Sensory room.
- Aromatherapy.
- Assisted access to swimming, horse riding and cycling activities.

Employment Placement;

- Facilitated access (via Job Coaches) to "open employment".
- Practical assistance, e.g. transport.
- Employment / Job skills training at one of the small business enterprises;
 - Telecottage** - Administrative Services to local and national businesses, Printing & Promotional Products.
 - Coverall** - High Quality laundering & ironing services.
 - Disability Equipment Stores** - a joint venture with local Health Services, maintaining and controlling equipment and stores.
 - Erlas Garden Project** - Contract Garden & Grounds maintenance. Plant nursery and Victorian Walled Garden Restoration Scheme. Closely linked to local Horticultural College.
 - Alyn Waters Country Kitchen** - Café Catering and general operation of Country Park visitor centre.
 - Lunch Run** - Snack & Sandwich Service.
 - Mill Farm** - Provision of Local Authority Meals on Wheels Service.



by Lloyd Nelson

Future Aspirations

The Service is committed to developing opportunities for its users to become more vocal and coordinated in speaking out against discrimination and misunderstanding, both by facilitating skill development, access and exposure, and specifically pushing forward the self advocacy agenda.

Leading by example, the service is looking to help the Local Council meet the 3% national target for the employment of people with disabilities by public bodies, would send a clear message to all.

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Erlas



Lunch Run



Mill Farm



Bridges

Small Business

A new Deal for Welfare

by Simon Cramp



So, the government welfare reform Green Paper, A new deal for welfare: Empowering people to work was published in January this year as part of a long term plan; I will attempt to give you the key points of this paper.

The paper includes much consultation in terms of people and organisations' responses, ranging from the Disability Rights Commission's 89 pages to individuals who have submitted a couple of pages of response. The House of Commons select committee for Work and Pensions has held meetings to look at different areas of the Green Paper and has produced a report. The government recently responded in June alongside their summary of the comments made to the green paper.

I recently attended a regional road show organised by Care Services Improvement Partnership (CSIP), and it was mentioned more than once there is no mention of learning disability in the Welfare Reform paper and people with a learning disability had to wait 6 weeks before an easy read version was published. The government accepted that this was not good enough and the time period for people to make comments was extended.

This policy has had a lot of press coverage but the focus has been very narrow, mostly discussing changes to incapacity benefit. But the Green Paper itself also seeks debate about housing benefit and helping parents with families get back into work and what impact this might have on other government policy like the health and social care White Paper, Your health, your care, your say. Some of the ideas around personal budgets and people wanting to work if given the right training or support are also reflected in the Green Paper. The key areas are:

- 1. Employment and Support pathways to work.**
- 2. Changing the rules on Housing Benefit.**
- 3. Getting doctors to give people the right support help and advice.**

It worth saying that apart from people with learning disabilities feeling they have not been mentioned in the Green Paper, most people think most of the ideas are going in the right direction although there is not much detail. But we now have a bill (a proposal to parliament) in which the government has asked parliament to look at the ideas that have come from the Green Paper. This is a consultation document and it is likely to take about 12 months for this to become law. There are a number of stages for this to pass through and doubtless

organisations and politicians will want to try and make changes as it goes though.

So watch this space, I am sure we will come back to this in future.

You can find the Welfare Reform bill and the green paper at <http://www.dwp.gov.uk/aboutus/news/#welfarebill>

Footnote

In the last issue of Community Connecting Simon had promised an article on 'managing the new realities'. This has been delayed because of the Cabinet re-shuffle. The new Minister for Health, Ivan Lewin and the new Minister for Social Exclusion, Hilary Armstrong will be looking into issues around vulnerable people. Simon hopes to report more fully when they have been more substantially in post.

Contact: info@communityconnecting.co.uk



A new deal for welfare:
Empowering people
to work

DWP Department for
Work and Pensions

John Down

The past has occupied my mind lately and the old adage that school days are the best days of our lives floated past and created a wave or three.

by Ros Jarvis



Of course children with learning disabilities were considered uneducable not so long ago and Junior Training Centres were their fate; the reason why many able older people with learning disabilities do not read. Not so in 1861 when John Hayden Langdon Down, the eponymous Down of Down's Syndrome, was working at Earlswood.

We tend to think that 'modern' is better but I would like to bore you all about the Victorian I would most like to meet.

John Down died in 1896 having devoted his life to people with learning disabilities. In 1853 he entered the University of London to study medicine where he distinguished himself as a student. In 1858 he obtained his MB London and the gold medal in physiology.

So, why did an outstanding young graduate accept the post of medical superintendent at the Earlswood Asylum in Redhill? Earlswood was the first institution for people with learning disabilities: before this they were incarcerated in the insane asylums where they were ill-treated.

Please remember that our language has changed. What is now considered derogatory was simply diagnostic or descriptive and we should not take offence. Where I quote, these words are simply the terms of the day and were not, and are not, intended to offend.

The charity that built Earlswood began in 1847 and its constitution stated:

"The design be, not merely to take the idiot under its care, but especially, by the skilful and earnest application of the best means in his education, to prepare him as far as is possible for the duties and enjoyments of life".

So, 159 years ago, they were emphasising education and having a life. What happened? Could our recent progress disappear too? History teaches us if we study, so here is some history to remind us that achievements can too easily be lost and forgotten. We need to make sure that ours remains.

John Down and others strove to make life better for people

with learning disabilities; to give them an education, training in essential skills and thereby a life in their local community.

There are several sources of information the house committee minutes, booklets of Reverend Sidney, newspaper articles, John Down's own writings and the personal journal of the schoolmaster that I found in the Earlswood museum and was allowed to borrow.

Reverend Sidney visited regularly:

"In the imitation room where the learners are taught form, colour and numbers, pieces of wood of all colours and capable of uniting to form figures and letters were ingeniously contrived and become in the hands of the untiring teachers, effectual instruments of instruction". Down stressed the need for building blocks in aiding learning.

Sidney noted:

"In the kitchen we found twelve of the pupils, not one of whom, a few years ago, could have been trusted near an oven or a fire" and *"We soon reached Redhill, and one of the first persons we saw on our way through the village was a pupil of the idiot asylum, who acts as postman"* So integration into the community is demonstrated here plus the benefits of earning a living.

The schoolmaster's personal journal was written as an aide-memoire and rough work book.

Extracts :

1862 - 31 pupils discharged - only two were wholly unimproved and twelve were so much improved that they were able to work for their livelihood. - They were discharging people back into their communities with skills for living.

1868 George Henry Barnes was admitted January 1864, knew no letters, no figures, counted to 4, knew no coins, weights, colours or writing letters. *"He now knows nearly all letters and reads slowly, counts to 58, knows all the figures, 3 coins, 7 weights, and 7 colours and can tell the hours by the clock."* By 1866; regular lessons were reading, writing, arithmetic, writing from dictation, shop-keeping, drawing, telling the time, object lessons, drilling, speaking and dressing.

Lesson length was deliberately varied from 30 to 45 minutes, interspersed with either singing or physical exercise. He says *"this combination of singing, physical and mental exercise is found to be very beneficial in awakening their attention and promoting cheerful attention to other subjects"*. No modern psychologist would take exception to this methinks. He describes the shop devised by Down : *"This lesson although considered play by the pupils is very instructive. A shop supplied with groceries, toys, stationery, and crockery and also counters, scales, weights and money is fitted in the schoolroom. The pupils are taught to purchase articles in common use. They act as shopkeeper in turn, weighing out articles required and endeavouring to calculate the price which is then counted out and paid by the pupil acting as purchaser."*

Down insisted his staff joined in the entertainments and it was a condition of employment. The schoolmaster's journal bears this out for in addition to his teaching role he seems to have been 'entertainments officer'. He organised, rehearsed and ran the brass band, the string band and the choral union and also various theatricals such as the annual pantomime. He was responsible for the monthly concerts and all major events and his journal provides glimpses of the backstage work as well as their public reception.

Down's own writings were for publication and are equally fascinating. He opposed slavery, supported equal rights for women and identified major causes of learning disabilities which stand today. He castigated doctors who assert the child "will grow out of it" saying on one hand it gave the parents false hope and on the other denied the child the advantages of early intervention. Anyone want to argue with that?

Down advocated a system of tongue gymnastics to improve speech and maintained that poor co-ordination can be greatly improved with training. Health, a good diet, daily skin care, well ventilated accommodation and frequent outdoor exercise were all vital plus the attitude of the staff.



Mary Reginald and family



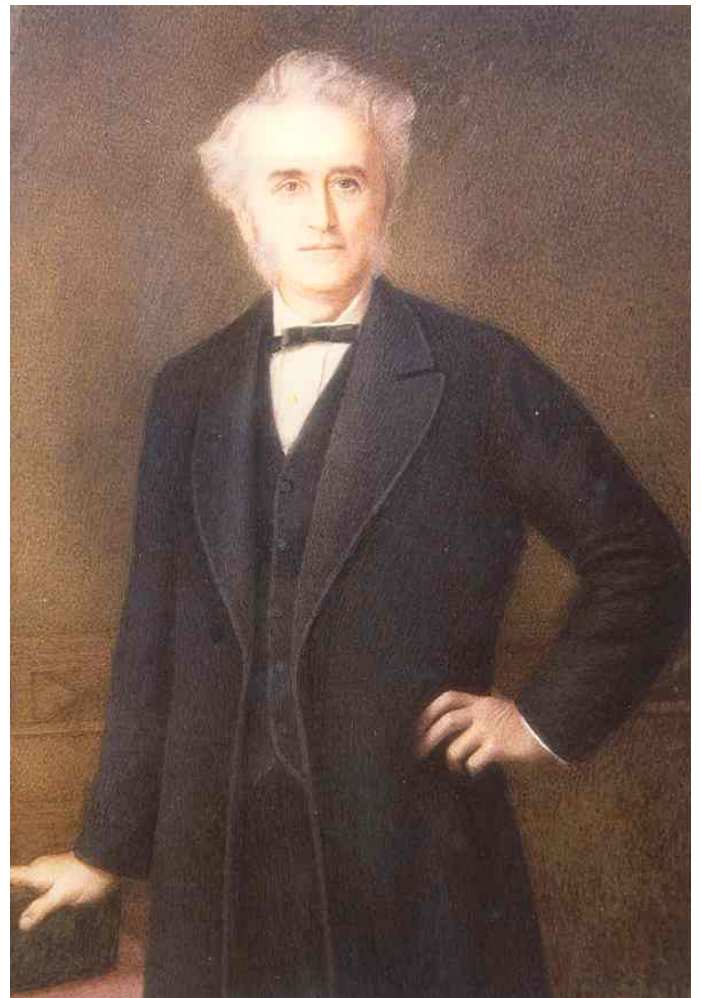
"The whole staff takes its tone from the head and that tone should be one of affectionate regard for the subjects of its care." I've met a few people who could do with taking that on board.

Of one deaf-blind boy of whom he wrote *"he smelled out his friends and manifested by a smile his consciousness of their proximity. That smile was always a reproof to us who have full possession of our senses for our occasional petulance at things of minor import, while this deprived boy never whined but appeared delighted at the most insignificant creature comforts."* Clearly Down was a recipient of that smile.

A reporter of the annual fete wrote that Down *"seemed to be held in special regard by the residents; by the spontaneous shake of the hand and warm smile of recognition marking something more than the relations which generally subsist between the dispensers and recipients of an ordinary medical or charitable asylum."*

He cared for them and they cared for him.

Contact: info@communityconnecting.co.uk



John Langdon Down

Photos supplied from the Langdon Down Centre Trust



Continuing the conversation:

Discovering the Soul of Our Community

Do we splinter into a million private sorrows or do we connect with each other and discover our strength?

A Parent advocate at an ACTION meeting

A group of families looked out over the array of living options for their young family members in Tucson, Arizona and were silent with fear. They were viewing the life of a “client”. “What a soulless existence,” they murmured to each other. Then they found their voice. “It doesn’t have to be this way. We can work together to create a better future”. One sister invited her brother to live with her rather than in a group home with three other people. Some families are combining their investments to create co-housing arrangements. ¹Still others do not yet know what they want and are still exploring possibilities.

Portraits of Community: In a way to create visions of possibility, a small group of families and friends banded together and designed a summer project called “Portraits of Community.” The project is based upon the principle of ‘Asset Based Community Development’, that the cup is “half full”. No matter how small the example of belonging in Tucson might be, the project group felt it was important to articulate a sense of hopefulness. They set out to collect a series of images of people, places, and events where individuals with learning disabilities feel a sense of belonging. These pictures will form a travelling photographic exhibit as a means of talking with local people, businesses, schools, service providers and others about what we can do together to make Tucson a place where everyone feels they belong - a more soulful place for all of us to live and call home.

A Self Determination grant of \$500 from CPES, an Arizona provider group, funded the project. This money will pay for fifteen disposable cameras, developing the film, and materials for creating scrapbooks and picture books of the photographs. Community Portraits project is divided into three events. Each event itself is intended to help promote a sense of community amongst photographers and their friends and families.

The first event was “A camera give-a-way”. One Saturday morning, we hosted a coffee morning to give away fifteen disposable cameras to aspiring photographers. They would have them for a three-week period. It was suggested that the photographers might consider taking pictures of people and

pets; of official places such as schools, work places, or banks; of places and events that interest them such as restaurants, clubs, sports events or summer parties; and also, of places around where they live such as their home, garden or neighbourhood park. These suggestions are specifically related to the five ingredients of Asset Based Community Development (ABCD): releasing the capacities of local people; associations; organisations; geography; and the local economy. ²It will be fun to see what the summer photographs show.

The Second Event will be a ‘Photo Share Party’. Each roll of film will be developed as a set of photographs and on a CD for flashing up on a screen. The gathering of photographs will be an opportunity for people to show each other their photographs. As part of the ‘Photo Share Party’ the group will select several photos to make into a hardbound book of pictures. Also, as part of the party, materials will be available for each photographer to make a scrapbook of their photos. This was a special request they made during the Camera Give Away. One educational programme offered to pay for developing the film which enabled us to use the grant money to buy the materials for scrapbooks.

The third event will be a Photo Exhibit. This will be in the late summer around the time that local students go back to school and to university. This is a time of great energy for new beginnings and fresh starts. Anyone who was involved in creating any of the pictures will be invited to the Photo Exhibit. For example, if someone took a picture at Ikes Coffee House or the Rose Garden Restaurant, the owners and staff of those places will be invited. We will be intentional about enabling businesses to see the benefits of providing a welcoming environment to people with disabilities and their families and friends. Part of the effort of this project is to shift the role of people with learning disabilities away from ‘client’ toward that of consumers and participants in everyday community life.

Challenging Conversations: The question we are asking in this project is: “What does it mean to belong in our communities?” Speaking personally, “belonging” means going places where they know my name. I will travel miles out of my

way to go the café or the post office where they smile when they see me and call me by name. In part they know me because I go there regularly and talk with the people who are serving me. No big deal, but it seems to matter. I also take my friends there. That helps business too.

Although we are still in the middle of the Community Portrait project there are many examples that have provided fuel for challenging conversations. One startling example happened the Saturday morning of our 'Camera Give Away'. Several people who wanted to come were not able to get there because their staff were in the middle of a shift change. This meant that the schedule for the aspiring photographers had to take a back seat to the transfer of information amongst staff. We delivered several cameras, but these individuals were not part of a gathering that was fun and a great opportunity to meet new people and see old friends. How do people outside the service sector get to know your name if your routines and rhythms are so dependent on routines and rhythms of others?

It will be exciting to see how the photographers define the essence of 'belonging'. The soul of our community will be much enriched by seeing what they see. Watch this space for

their images and definitions. Perhaps friends in England will also want to create their own Community Portraits. Please share!

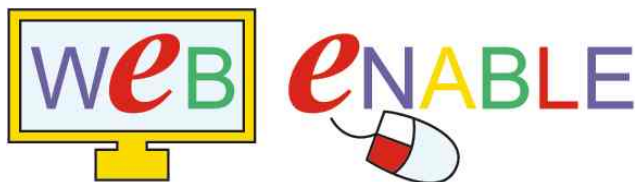
Let's continue the conversation. All comments welcomed.

Contact Nan at: nancarle@cs.com

Nan Carle, Ph.D. is currently a Commissioner of Services for People with Developmental Disabilities in Southern Arizona. Formerly she was Fellow in Organisational and Community Development at Kings Fund College in London, England and General Manager of Services for People with Learning Disabilities in Lewisham and North Southwark. She is a founder and former chair of Choice Support. She would enjoy hearing your stories and ideas for continuing conversations. She returns to England in May and November each year.

¹See Carle, Nan. "Growing a Sense of Belonging" in *Community Connecting: Valuing People With Learning Disabilities. Issue 5: Summer 2006: London, England.*

²McKnight, John & Kretzmann, John. *Building Community From The Inside Out: A Path Toward Finding and Mobilizing a Community's Assets.* Chicago: ACTA Publications. 1993.



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Association for Supported Living

What is the ASL?



The ASL is a not for profit association comprising of support providers and housing associations, in England, providing supported living for people with learning disabilities.

The purpose of the ASL is to extend the opportunity for supported living to all people with learning disabilities who seek supported living as part of their preferred lifestyle.

The role of the ASL is to broker the progression of supported living based on the collective membership of committed provider organisations, and other interested groups or individuals.

The objectives of the ASL are:

- To provide a central source of support, information and knowledge-sharing amongst all participating members.
- To address the key barriers affecting the development of supported living as they are seen by members.
- To lead on the development of best practice as it relates to supported living.
- To advocate for supported living as an accessible lifestyle option for people, irrespective of how much support they need to live their daily lives .
- To influence the development of national policy through dialogue with government and its agents for change.

How does the ASL achieve its objectives?

The ASL represents the views of its members to government and other agencies, at a national level. The ASL is a member of the Department of Health's Learning Disability Task Force and the Commission for Social Care Inspection's Learning Disability Improvement Board. The ASL, on behalf of members, has opened dialogues with the Office of the Deputy Prime Minister (Supporting People), and the Valuing People Support Team. Each year the ASL holds a national conference, in Manchester, and other member consultative events. In partnership with the Valuing People Support Team the ASL commissioned Paradigm to revise the REACH standards. REACH 2 defines supported living for people with learning disabilities and is an extremely useful tool to help provider organisations ensure compliance with Domiciliary Care Standards and Supporting People.

Why join the ASL?

Any organisation providing supported living for people with

learning disabilities that aspires to meet the REACH 2 standards may join the ASL.

The current member organisations of the ASL support over 14,000 people with learning disabilities with combined annual budgets of over £500 million:

Benefits of membership of the ASL include:

- Membership of the only national network dedicated to promoting supported living for adults with learning disabilities.
- A free place at the ASL's annual conference and additional discounted places.
- An opportunity to shape the development of supported living at a national level.
- An opportunity to express your views on issues related to supported living directly to the government and its agencies.
- Copies of REACH 2 at the ASL member's rate of £20.
- A range of networking opportunities at regular organised ASL events.

Membership fees

Less than £1 million turnover £250
 £1 million - £5 million turnover £500
 £5 million plus turnover £750

Contact details

Di Denham
 ASL Administrator
 c/o Advance Housing and Support
 2 Witan Way
 Witney
 Oxfordshire
 OX8 6FH
 Tel: 01993 772 885

Contact: diane.denham@advanceuk.org

The Housing Options hotline keeps a record of what people ring about;

The Housing Options hotline keeps a record of what people ring about; mostly it is about finding a place to live, a lot about money and benefits, but quite often they just appreciate someone to talk to. There are a lot of people who ring us up with general housing enquiries and we have to say that we specialise in helping people with a learning difficulty. There are also a number of Local Authority advice services called 'Housing Options' and we get muddled up with them. Then there are those people who aren't sure what they need to know but just want to talk to someone: for example, parents at their wits end who have been suddenly told that their son, who ten years ago was found a home a few miles away, after great struggle and



deliberation, is now expected to move back to where he came from.

"It was so difficult to find the right place and he's happy there. Why does he have to move again?"

Other parents, likewise, don't know where to begin:

"We've been told there isn't anything for him so he'll have to stay at home."

The Housing Options line is probably not without its hiccup's but we are regularly told:

"Well at least you answer the phone, all the others either don't answer or they say they'll ring back and don't, or people are unavailable 'in a meeting'."

People often just need to talk. To have another person listening can be enough for someone at the beginning of their search for help. They are so grateful, faced with what for them may be very complicated and worrying, that you sympathise and understand and maybe can give ideas of what they can do next.

We can vouch for the treatment people get from our own direct experience when acting on someone else's behalf. You find the office you need is unobtainable; the staff unavailable; the person on annual leave; the phone continually engaged; the Carers Helpline is only available from 11 am till 3 pm on Tuesdays and Fridays; correspondence goes unanswered for 4 months until after a complaint to the Town Hall a reply comes saying:

"I do apologise, the person you wrote to is away this week."

How often is it like that? Are Housing Benefit Offices always engaged? Are Social Workers and Housing Managers ever available to take calls? Do the Department of Work and Pensions keep you properly informed? Are you required to produce for the third time evidence of your eligibility for Income Support or the state of your building society account? How many times have you heard that the paperwork is 'missing'?

At Housing Options perhaps we should spend some time documenting the experience of the consumer dealing with services, sorting out housing or support for living or money. If you want to tell us about your experiences for better or worse you can tell us on:

enquiries@housingoptions.org.uk

HOUSING
OPTIONS



by Maurice Harker,
Housing Options

National Network for Learning Disability Nurses: *Annual Conference Report*

by Caron Thomas, Chair, NNLDN



It's that time of year again!

The National Network for Learning Disability Nurses (NNLDN) held the 24th annual networking event for learning disabilities nurses on July 3rd and 4th this year at the University of Ulster in Northern Ireland. The theme of this year's event was 'Transforming Learning Disability Nursing Practice'.

Throughout the conference speakers demonstrated how policy has been translated into new ways of working; how service user engagement in services has improved communication and experiences of service delivery, particularly in relation to health needs such as diabetes and long-term conditions. Amelia Jones, last year's Foundation for Nursing Studies award winner took centre stage with a well received presentation of her work entitled, 'Death and Dying: the Development of Person-Centred Approaches to End of life Care for People with Learning Disabilities' (featured in issue 5 of **Community Connecting** magazine). Amelia works as a community learning disability nurse in the South West of England.

The interim results of the NNLDN web-based survey on networks was presented by Paul Horan from Trinity College Dublin, who carried out the survey with Fiona Law from University of Wales, Bangor. A fantastic response has been received from the survey from learning disability nurses who are outward looking and interested in what other practitioners are doing in relation to translating strategy into reality, and using their experiences to facilitate good clinical practice. We look forward to the publication of the final report.

This year's event was a great success and was positively evaluated by delegates with some excellent concurrent presentations from practitioners, which really stimulated debates about strategy, education, leadership, clinical practice, and really engaging people with learning disabilities in service developments. This is the first year that the network has run master classes for writing for publication, building evaluation into projects, and practice development.

Martin Bradley, Chief Nursing Officer for Northern Ireland presented the challenges facing learning disabilities nurses across the UK and the Republic of Ireland from a variety of perspectives. Learning disability nurses were encouraged to build on past and current successes and recognize the socio-economic factors affecting practice and service developments, including changing demographics, the transition of care, the policy agenda, education and training needs, and the need to strengthen therapeutic interventions.

This message was supported by Professor Roy McConkey from

the University of Ulster, who entertained the audience with a very engaging extinction or evolution theme to his presentation which acknowledged how learning disabilities nurses had evolved up to the present and needed to continue this process through looking around at the changing environmental factors affecting health care and delivery.

Following on from the launch of the consultation document, 'A Vision for Learning Disability Nursing' at last year's event in Scotland, the United Kingdom Learning Disability Consultant Nurse Network presented the final document entitled 'Shaping the Future: A Vision for Learning Disability Nursing' designed to address the invaluable contribution that nurses can continue to make for people with learning disabilities and their families. The PDF version of the document will be available on our website and we urge nurses, service users, carers, educators, managers, researchers, and commissioners, to read it, so that the vision document can be used as a template for the development of learning disability nursing practice in an ever changing macro environment.

Student nurses continue to carry the torch in moving the boundaries of nursing practice forward and are our leaders of the future. This year the core group was able to secure three delegate sponsorships for student nurses from Choice Support, South London and Maudsley NHS Trust, and Learning Disability Practice magazine. Student nurses were required to submit an essay, and the overall winner was Sarah Coverdale from East Yorkshire, who will receive £250 from NNLDN. Conference delegates voted for the best poster display and an award of £100 worth of book vouchers went to colleagues from North Wales for their breast-screening project. Roz Taylor from The Foundation for Nursing Studies presented a much valued award of £1,000 for innovation in learning disabilities nursing practice to Mary Codling from the South of England, who will present the outcomes of her work at next year's conference (our silver jubilee!) which is to be held at the University of Bath on 2nd & 3rd July 2007. That's it for another year folks; the conference was uplifting in that so many people were hungry for information to take back to their workplace and share with others with the intention of improving standards of care and services for people with learning disabilities and their families.

If you would like to become a member of NNLDN, please visit our website: www.nnldn.org.uk

Contact: Caron.Thomas@ssh-tr.nhs.uk

Are employers missing out on skilled workers?

Employment opportunities for adults with Aspergers Syndrome and/or autism

CIC, a national social care provider has recently set up a task force to explore service provision for adults with Aspergers Syndrome and/or autism.

by Pauline Gay, CIC Communications

CIC, a national social care provider has recently set up a task force to explore service provision for adults with Aspergers Syndrome and/or autism.

Alice Drife, CIC Assistant Director, Learning Difficulties and Mental Health Services, heads up the national task force. "CIC has a person centred approach to service delivery, therefore we work with the individual and look at their perception of themselves before we consider their diagnosis. This approach means that we can build a menu of support around the person's needs and ambitions and access opportunities that may not have been available to them before."

Many of the people who access our learning difficulties and mental health services have autism or Aspergers Syndrome. Some have been

diagnosed, others have not. CIC's Autism Task Force is working with organisations such as the National Autism Society to further develop our services and to consider appropriate accreditation for some of the services we provide.

'Vocational opportunities' is an exciting area of support that CIC's Autism Task Force are exploring.

A study commissioned by the Scottish Executive to inform "The Same As You" National Implementation Group in Scotland (2005) found that: "when employing people with learning difficulties (and/or autism), without exception, the impact on the company had been one of raising their profile and they had been pleasantly surprised at the response of their other staff. Employees with learning disabilities and/or autism were frequently referred to as a 'real asset.'"

Howard Rice



Howard Rice manages CiC's Vocational Support Services and is a member of our Autism Task Force. He believes that too many employers are unaware of the skills that people within the autistic spectrum and, specifically those with Aspergers Syndrome, can offer.

Howard says: "Only 12% of people with Aspergers Syndrome are in full time paid employment (www.as-if.org.co.uk). The strengths of people with Aspergers Syndrome or who have been diagnosed as autistic can be many and varied. Their meticulous attention to detail in some cases can be exactly the kind of quality required for certain job roles."

Writer Tony Atwood commented in his book; *Aspergers Syndrome: A guide for Parents and Professionals*, that; "people with Aspergers Syndrome have gone on to achieve careers in the areas of art, science, engineering and computing and have contributed to many of the great advances in these areas."

Richard Meyer, who was diagnosed with Aspergers Syndrome in 1997 shares his experiences and helps others to achieve their employment ambitions. In his book *Aspergers Syndrome Employment Workbook*, Meyer helps people to identify their strengths and weaknesses for work including how to self-advocate and deal with disclosure.

Howard says: "Recently CiC's Vocational Support Service have supported a young man who works in a kitchen preparing food and helping out with general catering duties. With the support provided from a

CiC Vocational Support Facilitator, Mustafa has achieved much greater levels of independence and enjoys his work. Because the kitchen team who work with Mustafa know him and understand how Aspergers Syndrome affects him, they are very understanding and supportive. It helps them to know they can contact us if there is anything either they or Mustafa need extra support with. Finding the right employment environment can mean the difference between success and failure for that person. That is why it's our responsibility to get it just right and identify any potential problems before they happen."

Most of the challenges encountered when finding appropriate employment for someone with Aspergers Syndrome centre around matching the right job for that particular person's abilities.

CiC's Vocational Support service draws upon research from the National Autistic Society's employment service; *Prospects*, which recommends "concentration on vocational profiling. It is important in the early stages to get as much information as possible about the person and try to find employment opportunities that are appropriate, realistic and achievable."

Unsuccessful work trials or placements can have a significant effect on the person with Aspergers Syndrome. This can play a pivotal role in shaping that person's attitude towards work and employment in general. Bad experiences without the right support can mean that individual may never want to work again.

Many of the challenges encountered by people with Aspergers Syndrome are those relating to being misunderstood by others. Howard points out "It is the lack of knowledge of particular impairments that can lead to misunderstandings. However, if we engender an environment of openness and learning about disability generally, and more specifically when working within social situations, we may find that some of the difficulties encountered can be resolved relatively easily."

CiC's Vocational Support Service understands how important it is to support the employer as well as the employee. We provide specific disability awareness training to the employer including members of staff who would be working with the person with Aspergers Syndrome. This form of training helps the staff understand and better support the individual whilst at work. Staff usually respond well as in Mike's case and make adaptations and reasonable allowances for difference.

"Much of the research on autism and Aspergers focuses on children and their educational needs. But there is much more research needed to be done on adults and employment." Alice Drife explains "CiC aims to lead the way in providing services that support people with autism and/or Aspergers to have a full life and we believe that employment opportunities are integral to a socially inclusive approach."

Pauline Gay,
CiC Communications
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Tel: 0151 422 5352 07870 584977

In the UK, the public sector has shown the greatest commitment to building a socially inclusive workforce with an increase in the number of disabled people employed.

In the UK, Data from the Labour Force Survey reports a four-fold increase in employment for disabled people between 1998 and 2004. This means that around 12 per cent of disabled people had public sector jobs compared with around 19 per cent of non-disabled people, an employment gap of 7 percentage points.

The statistics also reveal that about half of disabled people of working age in the UK are in work (50%), compared with 78% of non-disabled people of working age.

Added to that, employment rates vary greatly according to the type of impairment a person has. Disabled people with mental health problems have the lowest employment rates of all impairment categories at only 20%.



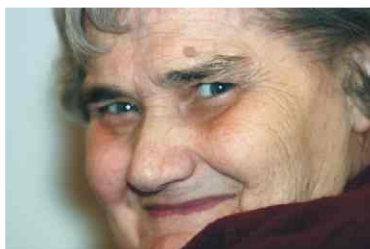
Mustafa Mohammed

Enhancing Dignity through Photography

Some service users have recently been involved with The Regard Partnership and Black Cab Studios in creating photographic portraits of themselves.

Some of the results can be seen here.

This whole exercise has proved very positive, not just in enhancing the dignity of individuals, but also in providing high quality framed photographic images for people and their relatives and friends.



The Regard Partnership also sought and obtained permission from all the service users to use some of their images to enhance the Reception area and Board Room of the company headquarters. This has served to constantly remind all visitors and staff about the prime purpose of our services.

The benefits that flow from creative photography can sometimes be neglected and this journal provides an excellent opportunity to enhance the dignity and self esteem of people we support.

When an older person says “this is the first framed picture of myself that I have had to keep”, it is a sober reminder of how much more needs to be done to support people to develop self esteem and a sense of dignity.

Rod Campbell



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Rod Campbell on 0791 338 7454

(Director of Communication and Development)

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