The background of the cover is a vertical rainbow spectrum with horizontal bands of red, orange, yellow, green, cyan, purple, and magenta. The text is overlaid on these bands.

SPECTRUM NEWS

30th Anniversary Edition

2014

Edited By Lesley Long-Price

Think you know
Disabled People...
Think Again

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Life.

**Life.
The space between
Soap operas.**

By Simon Brienden, founding member of SPECTRUM

From the Editor: Lesley Long-Price



This 30th Anniversary Newsletter provides spotlights by SPECTRUM people on some of SPECTRUM's major work and projects in the year 2014. SPECTRUM the organisation is a creation that is greater than the simple sum of its 'parts'. Its strength is in the synergy of these 'parts' "working together" to produce great things.

Firstly, SPECTRUM's Chief Executive, Ian Loynes, provides a round-up of the organisation's activities and major events in 2014. SPECTRUM's Business Development Manager then reports on SPECTRUM's service development plans.

This is followed by a section titled, 'Essays on personalisation and Independent Living', where Robert Droy and Teresa Burnage provide essays on Disabled People and the personalisation agenda past and present. Frances Hasler, as a guest writer, provides a follow up on John Evans' tribute celebration hosted by SPECTRUM in January 2014.

Then there is the first of our spotlights on SPECTRUM's diversity and skills at delivering activities and projects. We work with children and families; we 'do' research and report on the Hampshire Cuts campaign; offer placements to student social workers in our student unit and; support new and evolving User-Led Organisations through our Hampshire contract. We do a lot more work than this but there isn't enough room in the Newsletter to include it all.

Our second spotlight is on our Co-Production work. Our work with Hampshire County Council at user-designed commissioning as part of the Home Care Competition with a follow up Guardian article by Peter Beresford is included. This is followed by articles about 2 groups developed and facilitated by SPECTRUM namely the Hampshire Personalisation Expert Panel and the Southampton Consult and Challenge co-production group.

We finish this Anniversary Newsletter by publishing a poem by Simon Brisenden, a founding member of SPECTRUM, called The Battle for the Elephant and Castle (July 28 1988), which reminds us of where we came from and how much there is still to achieve.

This Newsletter is a companion to the book, 'SPECTRUM Our History. 30 years of Independent Living 1984—2014'.

Happy 30th Anniversary SPECTRUM from one of your very proud 'parts'.

Chief Executive's ROUND UP OF 2014

As Chief Executive of SPECTRUM CIL and on behalf of the Management Committee, Staff & Volunteers of SPECTRUM CIL, I am proud to welcome you to the 30th Anniversary Edition of our Newsletter.

Other articles in this Special Edition cover SPECTRUM's project work in 2014, and our development plans for the future. So, in my article, I'll focus on rounding up the developments in SPECTRUM during 2014 – including a dip into our history.

For readers interested in finding out more about SPECTRUM's rich and varied history, we are launching a "*SPECTRUM – Our History*" book on our 30th Anniversary (6th November), celebrating the history of SPECTRUM, and chronicling the development of Independent Living in the UK. (Which also started in 1984)

It really is hard to comprehend that SPECTRUM is now celebrating its 30th Anniversary. When I joined in early 1995, we had just celebrated our 10th Anniversary.

In those first 10 years we had done great things, going from our 'birth' at a meeting with half a dozen Disabled People and a £100 grant, to an organisation that employed 5 people. That was impressive enough...



Ian Loynes: in 1984



in 1995



in 2014

ROUND UP OF 2014

continued

Now, as we reach our 30th Anniversary, we have so many more amazing achievements to celebrate. At a time when many User Led Organisations (ULO's) are struggling to survive, we have a thriving, diverse and innovative organisation that runs a wide range of Independent Living Services:

- We support the development of new User-Led Organisations
- We train and mentor Student Social Workers of the future
- We provide a Direct Payment Support service, including the piloting of Pooled Budgets, Individual Service Funds and managed budgets
- We provide an on-line PA Noticeboard
- We support Disabled People and Local Authorities to work together, co-producing new services that meet the needs of the people who use them, at a cost the Council can afford;
 - In Southampton we call it 'Consult & Challenge';
 - In Hampshire we call it the 'Personalisation Expert Panel'
- We provide volunteering opportunities and personal development training for Disabled People looking to gain confidence, skills and opportunities
- We are developing a computer suite, which will enable Disabled and other people to develop I.T. skills that are essential for employment opportunities and for social and personal enjoyment in our modern society; we will also work with another organisation to show people how 'Assistive Technology' can enable them to access and use computers and the internet
- We run an advocacy service, supporting Disabled People to achieve their rights and have their voices heard
- We run a money management service, supporting Disabled People to manage their finances & prioritise the repayment of their debts
- We run an agency that supports people to use Personal Health Budgets (through our subsidiary organisation: SCIL Continuing Care)
- We own our building, renting offices to other organisations that promote Independent Living, and providing an accessible conference and meeting venue (through our subsidiary organisation: Unity 12)

ROUND UP OF 2014

Continued

All together, in 2014, including our two subsidiary organisations, we employ over 50 people and our income totals £1.3 million a year.

But most importantly, we still follow closely the original aims, philosophy and values that were formulated back in 1984; peer-based, run and controlled by Disabled People – and most importantly, accountable to Disabled People.

In 1984 ‘they’ said we couldn’t live independently or run our own organisations. I think in 2014 we have conclusively proved that we can... and that we do!

We should all be proud of what we have achieved as Disabled People.

I for one, wish I had aged as well as SPECTRUM!

Celebrating 30 years of Independent Living

During 2014 we have organised several milestone events to celebrate the 30th anniversary of SPECTRUM and the development in 1984 of Independent Living in the UK:

First, a celebration (see also pages 28-29)

To kick the year off, in January, we hosted a celebration of John Evans OBE’s ‘escape’ from residential care in 1984. John was the first person in the UK to employ his own Personal Assistants and live independently. We all had a great day and high spirits helping John to celebrate this achievement – and this was achieved with surprising low levels of alcohol!



ROUND UP OF 2014

Continued

Then, a study visit

In September we hosted a study visit from the European Network on Independent Living (ENIL) with 8 delegates from all over Europe, learning and working together to improve Independent Living opportunities across Europe. In the evening we organised a cultural tour of Southampton (i.e. we went down the local pub!)



Followed by a conference

In October we organised a Hate Crime Conference in Winchester in partnership with the Police & Crime Commissioner, and Hampshire County Council. It is only in recent times that the Government has properly accepted that Disabled People also experience Hate Crime. This conference aims to build alliances with other groups of people who experience Hate Crime so that we can work together to tackle this invidious and increasingly common crime in our modern society.



We also commissioned some research

In the current climate of economic, social and political angst, many Disabled People are experiencing cuts to services, cuts to benefits, often from many different directions, all impacting at the same time. As our recent research report into the impact of cuts on Disabled People shows (see pages 34-39), Disabled People have been the hardest hit by welfare reform; many people report that they are feeling fearful and depressed on a daily basis at their prospects of remaining independent.

ROUND UP OF 2014

Continued

Our main event – our 30th Anniversary conference

With this in mind, on November 6th – the actual date of our 30th Anniversary - we are organising a landmark conference to look at the future of Independent Living. Our conference consists of two parts:

Part one: celebrates the amazing achievements of the first 30 years of the Independent Living Movement;

Part two: provides an opportunity (by way of a 'Question Time' Panel) for Disabled People and other prominent experts, to examine the threats and opportunities for Independent Living in the future.

SPECTRUM has always claimed that independence is cheaper and more cost-effective than traditional 'dependency' based services. We hope this conference will help us to develop innovative Independent Living solutions for the future, just as we have done in the past.

Updating our information provision

Access to Information is one of the most important basic rights for Disabled People who want to live independently. SPECTRUM believes that information is power and that we should use all available technology to provide the highest quality information on Independent Living.

With this in mind, SPECTRUM launched its first ever website way back in 1999 (Surprise, surprise for our 15th Anniversary!). Whilst we have refreshed our website and added social media options since then, we are using our 30th Anniversary as the ideal opportunity to completely revamp our website and social media presence. We have committed significant resources and time to ensure that our new website meets our commitment to providing high quality, relevant and up to date information on all aspects of Independent Living. The new website will be equally relevant to Disabled People and to commissioners of services. We plan to launch our new website during our Anniversary year.

ROUND UP OF 2014

Continued

Finally, we have our AGM – and we know how to P A R T Y !

Talking about the AGM (see what I did there!), SPECTRUM's AGM will be on Saturday 8th November 2014. We will be holding our AGM in the afternoon for the first time.

So to mark the occasion, come and enjoy a real Cream Tea with SPECTRUM, learn what we have done this year and find out what we are planning to do; and if you are a full member, you can vote on who you want to represent you on your Management Committee.

AND IF THAT IS NOT ENOUGH FUN(!), our AGM will be followed by our 30th Anniversary Party – food, booze, music and Karaoke - amongst friends. (Please note the deliberate separation of music and Karaoke!!)



No-one can say we let our 30th Anniversary go unnoticed, can they?

ROUND UP OF 2014

Continued

Achieving SPECTRUM's potential – securing our future

In January 2013, we changed our name from Southampton Centre for Independent Living, to SPECTRUM Centre for Independent Living - a change that reflected the diversity of the modern organisation that we are, and at the same time dispel the misconception that we only work in Southampton - we have never just operated in Southampton.



From this logo



To this logo

Our name change has been an amazing success – signing up many more members, providing a wider range of services and working with people and organisations we have never worked with before.

However, changing our name in isolation would not ensure a future for the organisation - so we also commissioned a new Business Plan, which was developed with input from all parts of SPECTRUM - users, members, Management Committee, staff and other stakeholders. This Plan was launched in 2013 at our October AGM - a strong and ambitious vision for the future of SPECTRUM.

But, a Business Plan does not change anything if we do not commit resources to enable the plan to be realised. By early in 2014, we began to accept the reality that our staff already had massive workloads, and consequently, it was hard in practice to find the time the plan needed to make it real; as a result we were risking our Business Plan just ending up on a shelf, gathering dust.

SPECTRUM therefore decided to use some of its reserves to create a new senior staff role of 'Business Development Manager'. Gerry Zarb's existing part time role was increased to full time to focus significant extra development time and resources to enable SPECTRUM to implement its Business Plan and realise the many opportunities out there for an organisation as unique and innovative as SPECTRUM.

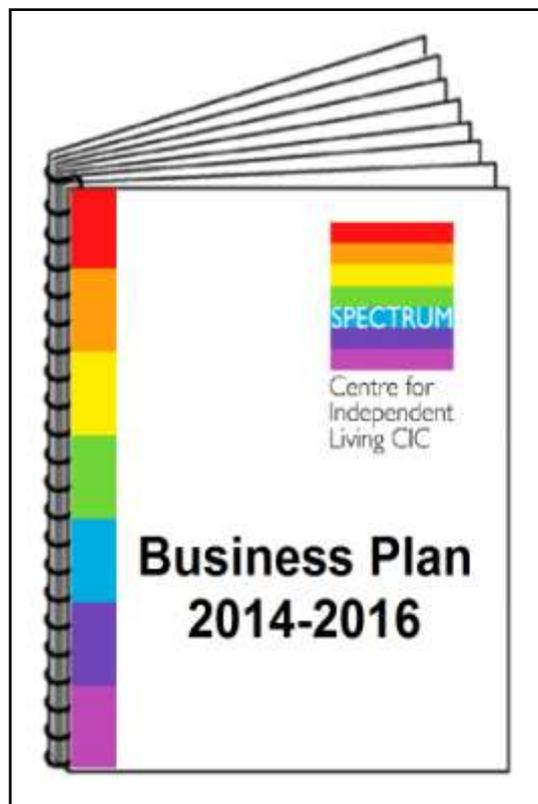
ROUND UP OF 2014

Continued

Infrastructure is dull – there's really is no getting away from it! But it is essential that we strengthen the foundations of SPECTRUM to enable us to cope with the growth of the organisation and the ambitions of our Business Plan.

We have been working hard on SPECTRUM's infrastructure; identifying what we need to improve to enable us to meet the demands the future will place on it. We have developed an 'Infrastructure Development Plan', created a 'Human Resources & Performance Management Sub-Committee', and agreed our first ever 'Reserves Policy', which will enable us to invest our reserves wisely to ensure we invest in our own future.

We believe with our Business Plan, Business Development Manager and infrastructure developments, we have an exciting future ahead of us, with realistic plans and resources to enable us to reach out and grab this future.



ROUND UP OF 2014

Continued

SPECTRUM has been nominated for *TWO* awards

AWARD 1: SPECTRUM has had two of its projects (Our ULO Project, and Consult & Challenge) shortlisted for the **United Nations' World Future Council's 'Zero' Awards** - Celebrating outstanding innovative practices from around



the world in the field of Independent Living and Political Participation. The United Nations recognise that there are one billion Disabled People worldwide; many of whom live in extreme poverty, survive in large institutions and have no access to decent work opportunities. In May 2008, the United Nations Convention on the Rights of Disabled People (UNCRDP) came into force, highlighting the importance of an inclusive society, in which Disabled People actively participate in the political, economic, social and cultural life. However, the lack of expertise on how to plan and execute policies that protect the rights of Disabled People, remains a major challenge. In response to this shortage, the World Future Council identifies exemplary policies and innovative practices in implementing the UNCRDP. We are proud to have had two of our projects shortlisted from a total of almost 300 entries from around the world.

AWARD 2: We have nominated ourselves for **Breakthrough UK's: 2014 National Independent Living Awards**. These are the UK's most respected awards for



individuals or organisations who 'go the extra mile' to remove barriers for Disabled People. Since 2008, Breakthrough UK has hosted these awards to celebrate the organisations or individuals that show a commitment and innovation to the independence of Disabled People.

As we go to press with this Special Edition, we await to hear if we have been successful with the Breakthrough UK award . But for the Zero Awards we have been invited to the awards ceremony in Vienna as 1 of the finalists.

Wish us luck!

ROUND UP OF 2014

Continued

SPECTRUM's future ... Disabled People's future

So, as we celebrate our 30th Anniversary, SPECTRUM has lost none of its drive, none of its innovation, and none of its ambition.

We do things – our way – Disabled People's way – the RIGHT way.

We truly do bring a different vision to the status of Disabled People in our society. I think our 'Strap Line' communicates this SPECTRUM vision well:

Think you know Disabled People ... Think Again

As we enter a very difficult social and economic climate for Disabled People, SPECTRUM remains one of the few organisations that provide modern, innovative, empowering and highly cost effective Independent Living solutions.

If you share our vision, we look forward to working with you now, and in the future.

Here's to the next 30 years!

From SPECTRUM's Chief Executive, Ian Loynes

A handwritten signature in black ink, appearing to read 'Ian Loynes', with a stylized, flowing script.

Service Development Plans

By Gerry Zarb



The challenges SPECTRUM faces

SPECTRUM Centre for Independent Living is one of the oldest ULO's, established in 1984. One of the reasons we have survived for so long is that we have always been able to adapt to changes in the world we operate in.

Being able to rise to new challenges has probably never been as important as it is now. The climate in which SPECTRUM operates has changed rapidly over the last few years with major changes in both the way User Led Organisations are funded and the way public services are commissioned and delivered. To thrive in this environment, we recognise that we need to become more enterprise focussed, strategically positioning ourselves to deliver services more focused on the benefits of the personalisation agenda, the Big Society, and welfare and health and social care reforms.

The challenge is to take advantage of the opportunities that lay ahead, whilst at the same time, keep the things that are important to SPECTRUM and our members.

Planning for a sustainable future

In order to plan a sustainable future for the organisation, in 2013 we commissioned a consultant from another Disabled People's User Led Organisation to help us produce a strategic development and business plan for the next three years. It was vitally important to make sure that the plan had input from all parts of SPECTRUM - Management Committee, staff and members – all of whom were involved in a thorough review of all our activities and services through a series of workshops and interviews.

We had to look critically at every aspect of SPECTRUM and accept that some things will need to change. The review was focussed on building on our strengths and addressing perceived weaknesses, and identifying potential barriers to our development and how we could deal with them. In particular, we wanted to look at areas that can be improved as well as new activities that could be developed in order to make sure that SPECTRUM remains relevant to its members and Disabled People in general, and to give us the best chance of a secure future.

Service Development Plans

Continued

The strategic review identified a number of areas for improvement, including how we promote the organisation; communication (both internal and external); information; outreach; and the way we develop new or expanded services.

For example, we identified a number of ways we could improve how we reach out to Disabled People and build our membership, including promoting SPECTRUM in other areas of the county via peer support groups; membership drives; attending information fairs; outreach surgeries or road shows; encouraging members to promote SPECTRUM and the benefits of involvement to their friends, and so on. We believe that these kinds of activities would demonstrate our ongoing commitment to provide awareness raising, support and information to Disabled People in their local communities.

We also identified a number of opportunities to build on the considerable experience within the organisation to develop some of our existing services and to branch out into new areas where our expertise could enable us to develop new services.

However, the review also highlighted that there is a lot of work to be done to equip the organisation to take advantage of these opportunities, both in terms of how we work and how we communicate what we are about and what we do to the rest of the world. For example, we need to establish a better focus on marketing opportunities (i.e. events, fundraising, workshops, seminars etc). We also need to overhaul and modernise our website and social media platforms. This is very important to enable more people to know that SPECTRUM exists and what it has to offer.

Our service development plans

All parts of SPECTRUM – Management Committee, staff and members – have a part to play in implementing our strategic development and business plans. To support that process, and to provide a clear enterprise focus in the organisation, we have created a new Business Development Manager post within our core management team. We have also set up a Website Redesign Group to design and commission a new web-site and to review all of our on-line communications activity.

Service Development Plans

Continued

One of the first tasks for the Business Development Manager was to establish priorities for service development. While the strategic plan identified a number of potential areas for developing new services and income streams, or expanding existing services in general terms, these needed to be examined in more detail and put in some kind of order of priority in terms of which specific options were the best fit for the organisation's aims, values and expertise and which were the most feasible to implement.

A number of specific options were drawn up based on the recommendations in the strategic review and an analysis of our existing activities combined with research on current market trends in areas compatible with our overall aims and objectives. We also researched potential sources of development funding for the various options. These options were then discussed with staff and Management Committee so that we could identify a short list of development priorities for the immediate future.

The consensus from these discussions was that, initially, SPECTRUM should focus initially on what we do best – building on existing expertise - and look to develop services in other areas over the longer term when we have built up skills and capacity.

It was also emphasised that we should avoid trying to do too much too quickly, as this had been a problem in the past. Rather, we should focus on a few areas in which SPECTRUM has the most expertise in order to be more effective.

Three main areas were identified as most suitable for priority development over the next 12 to 18 months:

- 1) Personal Budgets and Direct Payments support and Personalisation in Care and Support
- 2) Advocacy and advice services
- 3) Employment support and employment related services

Service Development Plans

Continued

It was also agreed that we would aim to increase consultancy and training activity in these areas, plus a limited number of other areas where it is felt that SPECTRUM has particular expertise (e.g. Disability Equality).

1) Personal Budgets and Direct Payments support

SPECTRUM has a long and successful track record of supporting Direct Payments users. However, only a relatively small proportion of people with Personal Budgets will be direct employers, so we need to continue to expand our offering to support a range of managed social care budget arrangements. It will also be particularly important to make sure that we are able to respond to the needs of Self-Funders, who will represent an increasingly large proportion of all social care users as eligibility for publicly funded support becomes even tighter. In practice, this will mean developing our current services to offer more brokerage and information and signposting type services, some of which would need to be adapted for, and targeted to, particular groups. We are more likely to succeed with this objective if we develop relevant partnerships and consortiums (e.g. with Older People's Organisations).

Personal Health Budgets

Personal Health Budgets are still very new but represent a potentially significant opportunity for SPECTRUM to utilise our expertise and knowledge of Personal Budgets and Direct Payments in social care. Personal Health Budgets are initially being offered to people with eligible Continuing Health Care needs, but will be rolled out across all user groups from 2015.

The potential demand for support and advice is high and this represents a significant opportunity to secure a reliable source of new income. For example, just on Continuing Health Care, there are nearly 2,000 eligible users in Hampshire alone.

2) Advocacy and advice services

We want to continue with our current advocacy and advice service, which provides vital support on a range of issues faced by Disabled People. There may also be opportunities to generate new income to support this vital service.

Service Development Plans

Continued

In particular, local councils are all likely to be commissioning a range of information, advice and signposting services to meet their 'Universal Offer' obligations under the Care Act to provide information and advice for everyone with care and support needs and not just people who are eligible for publicly funded support. There will be stiff competition for this kind of work but we believe that SPECTRUM has plenty to offer.

Subject to building our capacity, there are also a range of more specialist advocacy services that might be candidates for development over the longer term such as Independent Mental Health Advocacy (IMHA) and advocacy for people subject to Deprivation of Liberty Safeguards.

3) Employment support and employment related services

The barriers to employment faced by both Disabled Adults and young Disabled People are well documented. If anything, these are even more pronounced in the current economic climate.

Clearly, therefore, there is little doubt that there would be demand for employment related support if we want to expand our operations into this area. For example, we are currently looking at offering support and training for Disabled People who want to learn new skills to increase their job prospects. There is also considered to be significant scope for developing services aimed at employers to assist them with supporting disabled employees and developing accessible, productive and non-discriminatory working practices and environments.

Service Development Plans

Continued

Next steps...

We are in the process of taking these ideas forward over the next few months. For each of our priority development areas, we are setting up dedicated small working groups to undertake any further research required, make contact with potential clients/funders and partners, examine the resource implications of each option, and finally to work up detailed action plans. The Business Development Manager will also support this process.

We are also carrying out a skills audit across the whole organisation so that we can assess what particular strengths and interests each staff and Management Committee member has; what they need to manage their roles in the most effective way; and how they would like to further develop their knowledge and skills in the future.

In addition to these 'nuts and bolts, practical issues, there are also some wider important organisational questions we need to think hard about. In particular, how we achieve the right balance between service provision and campaign and advocacy work, and how we can ensure that the resources we need to put towards service development and income generation do not compromise these other core activities. We also need to consider how we can diversify the range of our activities and user base while, at the same time, maintaining a clear focus and identity.

So, there are many challenges ahead and plenty of work to do. Change is never easy - but the potential rewards will make the effort more than worthwhile. We can draw a lot of strength from our experiences over the past 30 years as we look ahead to challenges and opportunities to come. Nobody knows for sure what the next 30 years will bring but, by focusing on sustainable development, we hope to make sure that SPECTRUM is still around to find out!!

Essays on Independent Living - Direct Payments

By Robert Droy

This year, SPECTRUM Centre for Independent Living celebrates its 30th anniversary. In 1984, Disabled People were just beginning their campaign to live independently. Disabled People in Hampshire were at the forefront of that campaign and have remained active participants in that fight.

In 1995, Disabled People were delighted when the legislation was finally passed which allowed local authorities to provide cash payments to Disabled People in lieu of community care services. This was called Direct Payments. This was the result of a decade-long battle which originated in Hampshire, where Disabled People wanted to exercise choice and control over who provided their support, when it was provided and how it was provided.

The Self Operated Care Scheme (SOCS) was pioneered in Hampshire in the 1980s and allowed Disabled People to employ their own Personal Assistants via payments which came from local authorities via a third party.

The flexibility SOCS offered gave Disabled People a real opportunity to live independently and soon Disabled People across the country wanted the same opportunity.

Despite its questionable legality at the time, the benefits of SOCS were obvious to see and central government and other local authorities started to take note.

In 1993, the Independent Living Fund (ILF) adopted a similar approach when supporting Disabled People with high support needs. Indeed, the ILF was so successful, that strict criteria had to be introduced in 1995 to limit the number of people who could access the fund.

Given this background, you may have thought that Direct Payments would have swept across England and Wales like a tornado, once the legislation was passed.

Unfortunately, this was not the case. Despite the government strongly promoting Direct Payments, many local authorities struggled with the notion that Disabled People could manage their own support needs more effectively than the Social Services Department.

Direct Payments

Continued

Whilst numbers slowly increased, it was not the widespread cultural shift that Disabled People had hoped for.

In 2000, people aged over 65 were able to access Direct Payments and the government increased the pressure on local authorities by altering the legislation to make it a legal duty for local authorities to offer Direct Payments.

There are many reasons why Direct Payments had a slow uptake and this varied across the country. Whilst SOCS offered a great deal of flexibility, the advent of Direct Payments also led to the introduction of a number of bureaucratic processes that had to be followed.

The financial monitoring processes introduced by some local authorities went from the sublime to the ridiculous. When SCIL was asked by one local authority in another part of the country, how they could increase Direct Payments uptake, we discovered users were presented with a 120 page booklet on Direct Payments to read before deciding whether to opt for Direct Payments. Not surprisingly, most people were put off by this.

There was also a growing tension between employment legislation, particularly Health and Safety, and Disabled People's human rights to live an independent lifestyle. Whilst this tension was tackled by some local authorities, others used it as another reason to discourage use of Direct Payments and maintain the status quo.

Whilst many Disabled People recognise the need to be accountable for how they use their Direct Payments, over the years, local authorities began to tighten up on how people could use their Direct Payments. This inevitably led Disabled People to feel the flexibility and simplicity that previous schemes like SOCS offered, were being compromised. There was also a widespread view amongst Social Workers / Care Managers that many users did not want to employ Personal Assistants and therefore would not benefit from Direct Payments.

Direct Payments

Continued

In the mid 2000s, in an attempt to address some of these difficulties, organisations like In Control started promoting a wider view of Direct Payments, particularly emphasising the benefits that they offered to Carers and the fact Direct Payments could be used for many more things than just employing Personal Assistants. The now infamous example of someone using their Direct Payments to buy a football season ticket demonstrated the flexibility that Direct Payments offered; however, it also provoked much debate, particularly in the media, about whether public money was being spent effectively.

A new set of jargon words also started to emerge – ‘personalisation’, ‘individual budgets’, ‘self directed support’. This apparent rebranding of Direct Payments was viewed with suspicion by many Disabled People who saw through the hype and felt the jargon merely took the focus away from the real issues facing social care; that of tighter eligibility and tighter budgets.

Locally, in 2008, Hampshire County Council launched a Commission on Personalisation which brought together local and national ‘experts’ to examine the future of adult social care in a series of hearings. Local Disabled People and their organisations were initially sceptical of the Commission; however, over the course of the Commission, users did get increasingly listened to as ‘experts by experience’ and the Commission’s final recommendations emphasised the importance of the local authority working in co-production with users in all aspects of Adult Social Care.

This led to the establishment of the Personalisation Expert Panel (PEP), which I chair on behalf of SPECTRUM. The PEP is a coalition of user-led organisations, carer-led organisations, and individual service users and carers who are committed to working in partnership with the local authority and the NHS, to bring about reform of social care and health care.

Over the last six years, the PEP has worked in an increasingly difficult environment as economic austerity and spending cuts have become the priority and Disabled People’s human rights have been sidelined by current government policy. Since the coalition government in the UK came to power in 2010, there has been a raft of measures such as the abolition of the Independent Living Fund and significant cuts to welfare funding and local government spending that fundamentally threaten Disabled People’s ability to continue to live independently within their community. (see page 54-59 for more information on the work of the PEP).

Direct Payments

Continued

Where are we left at the end of 2014?

As SPECTRUM Centre for Independent Living enters its 30th year, it is clear that there is still much to be achieved for the Independent Living Movement. The Independent Living Fund is set to close by 2015; Direct Payments have steadily increased but has not been the 'game changer' that many Disabled People had hoped for. This is largely because they have been viewed by many people as bureaucratic and no longer offering the flexibility, choice and control that Disabled People once enjoyed.

The coalition government has also just introduced new legislation that will affect the whole of the social care sector. The Care Act (2014) seeks to unify over 20 separate pieces of legislation concerning social care into a single piece of legislation. In theory, this should make it easier for Disabled People and carers to understand what their legal rights are; however, the draft guidance is vague and could create unforeseen legal loopholes. The bill will be implemented from April 2015 onwards so only time will tell.

There are also massive changes to the UK health service taking place currently with an increased focus on integrating social care and health care. Again, this could be a positive step if the aim is to deliver better outcomes for people rather than just trying to save money.

Direct Payments – The Future?

Despite the doom and gloom, SPECTRUM believes that the basic concept of Direct Payments is still a sound one. We have seen many Disabled People over the last two decades become empowered by having choice and control over how they receive the support they require in order to live independently.

We will continue to fight for all Disabled People to have access to Direct Payments and hope that the era of Direct Payments is far from over.

Essays on Independent Living - Personalisation

By Teresa Burnage

Personalisation is described by the Department of Health as meaning that “every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings”.

This is usually delivered through Self Directed Support (Direct Payments and Personal Budgets) to enable service users and carers to choose the services they receive. It can also be self-funded for those that don't meet current eligibility criteria or have yet to apply for a funding assessment. Personalisation also requires that services be tailored to individual needs and not a general offer.

Personalisation also aims to improve preventative services, speed up the delivery of assessment / support, provide clear information, promote independence and maximise social / community capital.

Choice and control will always have limitations, often in the form of access to available, affordable services and the support of eligible needs only. There are always choices to be made as it's unlikely that any individual will receive funding for their 'wish list' so prioritising becomes an important aspect of any support plan to ensure the best outcome. In previous years, service users and carers may have had enough of their own funds to pay for additional support / activities or services to sustain their wellbeing and fill in the gaps. However, the increase in care contributions, often around 100% of disposable income, have led many recipients to give up these. We are finding that this may often include the ability to afford travel to community groups (even if free to attend), internet access, domestic support and gardening.

Austerity measures imposed on local authorities have led to significant cuts in funding social and emotional support, domestic help and assistance with cooking.

Funding is available for essential personal care and service users are encouraged to transfer from agency support to direct payments. Whilst this offers a degree of choice, there may be little flexibility on a very tight budget.

Finding Personal Assistants to replace short agency calls such as 15-30 minutes for medication, showering etc is very difficult, even if the service user is based in a large city. PA's have to pay their own travel to and from work, often making short calls unprofitable.

Personalisation

Continued

Care providers have had to change their approach as councils pass purchasing power to service users who can move their support if they're unhappy with services provided. Providers can no longer rely on steady business levels and block contracts that they once held with local authorities. Councils are negotiating framework agreements, accrediting providers to set out price and quality standards. Providers will no longer have guaranteed business and will need to be receptive to the needs of their service users, hopefully leading to continued improvement.

As the concept of personalisation is constantly developed through legislation, it still remains that local authorities are not provided with sufficient funding to progress many of these good intentions. It is going to be increasingly important for support and community organisations to join forces, share expertise and ideas to survive under the weight of current cuts.

Very few organisations have sufficient funding or fundraising capabilities to provide support in all areas relating to furthering independent living in the current economic climate. Sharing best practice, resources and creative ideas will maximise economies of scale and sustainability.

For example, SPECTRUM are developing an accessible IT suite to support and train service users to use technology positively for shopping, employment, online training, social networking and accessing services such as e-books etc. This could potentially provide an opportunity to 'time bank' with other organisations, swapping trainer time, resources or equipment to use the suite.

Some service users would like the opportunity to consider the option of technology or equipment rather than a Personal Assistant for 2-3 hours per week through their Direct Payments. This could mean an adapted tablet for a visually impaired person enabling them to read their own mail / magazine articles (image zoom), shop online themselves, access e-books (some free through libraries), social media etc.

The next 5 years will provide further legislation to further the personalisation agenda. To be a part of implementing and positively applying that change, we will all need to be more collaborative, innovative, flexible and able to listen to the views of service users and provide sustainable solutions. It's going to be tough but SPECTRUM is open to new ideas, new partnerships and looking forward to the future (head on!).

Essays on Independent Living - 30 years of freedom

By Frances Hasler

Reflections on 30 years of freedom

Photo: Frances Hasler and John Evans,
Bar Le Duc on route to Strasbourg, April 1989



A “festshrift” is an academic word for a book honouring someone’s work. The festshrift usually includes contributions from significant people, celebrating the life and work of the subject, and sometimes a selection of the person’s own writings. It is often presented at a special event. The gathering at SPECTRUM to mark 30 years since John Evans left Le Court, could be described as a sort of festshrift event. John’s friends and associates from several decades of activism were there. As is fitting for John, the participation was international, with video contributions from Europe and America. A book, collecting together his speeches and articles, and with commentary from many key figures in Independent Living, was compiled. John’s achievements were noted in affectionate tributes.

John’s family were there, reminding us that he comes from an ordinary background and achieved his status not through privilege but through his own determination to travel, to explore ideas and to share his life with like-minded people. His story is also a reminder that no-one achieves things in isolation, we are all borrowing and adapting each other’s ideas and we are all stronger if we work together.

The event was a good opportunity to take stock of the UK Independent Living Movement, and John’s contribution to it. Among the participants were former officers of Hampshire County Council. They were people who had taken a chance on doing something new because they could see the potential for producing something better. They had faith in John’s quiet persistence, they became allies of the movement. Judy Hunt was there, too, remembering her husband Paul, who inspired so many Disabled People to challenge the idea that residential care was the answer to their support needs. Paul and his colleagues helped to reframe thinking on the meaning of disability. They made it possible to see Independent Living as choice and control, rather than being able to do everything for yourself.

30 years of freedom

Continued

The event was a great opportunity for me to catch up with old friends, look at old photos of demonstrations, European conferences, and the launch of the National Centre for Independent Living. I first met John in 1980, in the company of his great friend, Phil Mason. They made a fine double act, pursuing serious intentions – getting out of Le Court, securing direct payments, creating Hampshire CIL – with humour and sociability. It seemed fitting that the idea for a 30 year celebration came about in a pub. They'd both been through some difficult times – John in intensive care and Philip's wife, Virginia, gravely ill – but still made the time to get together for a convivial lunch with old friends. And that to me is the essence of what Independent Living is about. Being able both to survive the tough stuff and to enjoy the fun stuff is what matters. Direct Payments, Personal Budgets, the twelve pillars of Independent Living are all tools. The thing we build with the tools is a life that is worth living.



Phil Mason

Times are hard for Disabled People at the moment, with attacks on welfare, shrinking care packages, organisations finding it ever harder to find funding. What this look back with John showed me is that persistence, clear goals, good friends and allies, can make things happen. Honouring one person, and his tireless work to spread the philosophy of Independent Living, is also a way of celebrating each and every person who has achieved the life they want with the support of the Independent Living Movement. It will, I hope, inspire us to keep going, even when things look bleak. The ideas of the International Independent Living Movement are too strong to destroy.

So, many thanks to SPECTRUM for hosting this event, and giving me the opportunity to reflect on thirty years of progress. Of course there is still work to be done. But every now and again it is good to take time out, and have a jolly fine party!

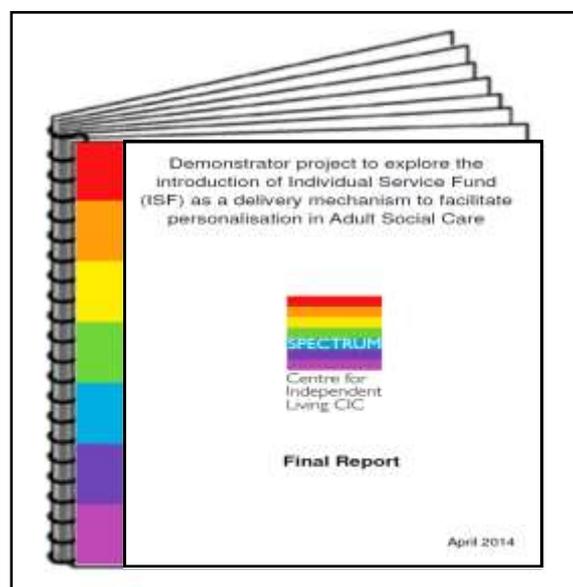
SPECTRUM work with children and families

By Lesley Long-Price

Southampton City Council, ‘Demonstrator project to explore the introduction of Individual Service Fund (ISF) as a delivery mechanism to facilitate personalisation in Social Care.’

Remit and aims:

SPECTRUM developed and delivered an Individual Service Fund (ISF) “offer” to individual customers of Southampton Children Services, Special Educational Needs and Disability (SEND).



The aim was to enable the benefits /disbenefits of the ISF to be identified from the viewpoint of customers (and their carers), providers and the local authority.

Evaluation Measures included:

- Customer choice and control over services
- Customer (and carers) satisfaction
- Culture change in relationships between customers, provider and the local authority
- Cost effectiveness

How we did it?

We worked with SEND customers who, in agreement with Children’s Services, wished to explore a different way of having their education needs met in preparation for fully integrated Personal Budgets (PB).

Our project identified and “tested out” the service practices necessary to constitute an ISF tailored for any individual as required. This included establishing the necessary individual recording and accounting systems to report to our customers and to enable an analysis of our own SPECTRUM costs in delivering the ISF service. Our project tested the costing premise of charging a % rate of the individual’s PB for the ISF service.

We employed an experienced SEND teacher to provide home education.

The principles of person-centred working and co-production governed service delivery, its monitoring and evaluation.

SPECTRUM work with children and families

Continued

Family Involvement in service delivery:

SPECTRUM recognised that family involvement (child where possible) was essential to the Person Centred principles of this service, and placed this involvement as a main priority throughout and worked hard to achieve this family engagement.

Managing the money:

SPECTRUM managed the ISF budget on the family's behalf. Detailed financial records using accounting software were kept. The ISF account was set up as a separate account on the accounts system so that all income and expenditure could be easily identified and accounted for. Detailed accounts records were produced on demand. The family received 6 monthly account statements and were involved with how and what to spend the money on. For example an i-pad (suggested by the parent) and specialist software were agreed as an educational need and purchased.

Other partners:

SPECTRUM worked closely with the SEND Inspector who offered support and guidance and was on the recruitment panel along with the parent for the recruitment of the teacher. Cedar School provided advice to SPECTRUM and supervisory support and professional training to our teacher. Our teacher worked with the child's Occupational Therapist, Physiotherapist and Social Worker. Multidisciplinary working was essential to working in a personalised, holistic way where solutions were co-produced across agencies. We also took into account non-service options accessed by the family.

How we evaluated the service:

We evaluated the service provision by using the Think Local Act Personal (TLAP) Markers. The 6 markers of progress are: 1) Information and advice; 2) active and supportive communities; 3) flexible integrated care and support; 4) workforce; 5) risk assessment and; 6) Personal Budgets and self funding.

We also evaluated any culture change in the working relationships between customers, providers and the local authority.

SPECTRUM work with children and families

Continued

Some findings:

- o Customer choice and control over service provision and delivery was demonstrated for our customer.
- o Customer (and Carers) satisfaction was demonstrated with very positive feedback from our parent on the delivery of service.
- o Culture change in relationships between customers, providers and the local authority was partially demonstrated in terms of some progress being made i.e. parent on recruitment panel and ULO organisation working with education. But this aim needs more testing.
- o Cost effectiveness; this needs further research as it can only be evaluated if compared to other potential alternatives and the Council needs to analyse cost factors of an ISF when compared to that of a comparable Council provided service. However, potential better outcomes need to be taken into account as a factor as well.

SPECTRUM work with children and families

Continued

Quotes:

"It's been an amazing experience. I am so pleased that this is happening. SPECTRUM are so very helpful. When I'm at work my child is safe and comfortable. The teacher is so good for my child, I would not change anything. The teacher understands our home situation."
Parent

In terms of the management of the ISF itself the parent reported they had enough information about SPECTRUM's role; the parent noted a key task of the service provision being: *"SPECTRUM with my approval manages the money, and takes the responsibility out of my hands."*
Parent

"At the start I had to offer advice on some education things for example child's likes and dislikes and how to hold the child correctly whilst being taught. I also joined in with some of the songs". But "the teacher is a professional and knows what she is doing."
Parent

The ISF provision and education in the home setting was reported by the parent as a service, *"...that met the needs of the child/family"*, that *"provided flexible support"*, and *"...included other professional input that worked together and the family were in control of."*
Parent

"The project has benefited enormously from the expertise that SPECTRUM already had around personalisation and also from their willingness to trial a completely new area in SEND personal budgets delivered through an ISF."
Development Worker, SCC

"SPECTRUM has always listened to the implications of any actions suggested to them. SPECTRUM's approach has been creative in problem solving. SPECTRUM has an attitude of no barriers and instead looked for solutions and has always had an enthusiastic approach to the project".
SEND Inspector

"The planning between SPECTRUM and the school has been good thus far and the contract set up between both providers has allowed professionalism and integrity with our particular working cultures but also much needed flexibility."
Head of Cedar School

SPECTRUM DO Research - Hampshire Cuts Campaign

By Berni Vincent & Gerry Zarb



SPECTRUM's history of campaigning for the rights of Disabled People is rooted in the British and international Disability Movement, born of the civil rights campaigns that shook the western world during the sixties. Our guiding principle has always been that Disability is a human rights issue.

Why the Cuts Campaign?

Over the years SPECTRUM has witnessed, at a grass roots level, how having the right funding transforms Disabled Peoples lives, enabling them to have choice and control and to participate in society. We have seen people blossom into active citizens taking their place in society.

In recent years, the austerity cuts have meant the hard won battle fought by Disabled People and our organisations for Independent Living has been under a real threat.

On a daily basis SPECTRUM are now hearing how Disabled People with limited resources are being forced to navigate the system often with inadequate funding for Direct Payments. We are also seeing a huge increase in the need for advocacy support and delays in accessing services due to government imposed cuts in local authority funding.

SPECTRUM's history, knowledge and experience put us in a key position to undertake a research project to test the cumulative impact of the cuts to services and funding on the lives of Disabled People. As a campaign organisation, we felt a responsibility to our members and local community to find out more, and establish the real impact.

In May 2013, a proposal was drawn up and presented to the SPECTRUM Management Committee – The Hampshire Cuts Campaign was born.

The Hampshire Cuts Campaign so far

The impact of the austerity cuts is having a damaging effect on the lives of Disabled People, families and Carers. Media interest and public awareness of the scale of the problem and what it really means for people's day-to-day lives, is fairly low. What media debate there is has often been distorted by an unhelpful and misleading view that Disabled People who claim benefits are defrauding the system and do not want to work.

Hampshire Cuts Campaign

Continued

What the campaign aims to achieve

The campaign aims to raise awareness of the real impact of the cuts in Hampshire and demonstrate a realistic and balanced view to the political and media debate. The campaign also aims to build alliances with other ULOs and allies including Hampshire and Southampton City Councils to create a stronger voice in the political debate.

Essentially, the campaign's key objective is to secure a commitment from local MPs to consider a partial reversal of the cuts.

During June 2013 to March 2014, 47 people in Southampton and Hampshire were asked to complete a structured diary and questionnaire detailing the impact of welfare reforms. All the people that participated in the research received a £20 voucher to thank them for their contribution. Some people commented that their involvement was not dependent on receiving a voucher, 'they were pleased to have their voices heard and have someone to talk to'.

We wanted to ensure we gathered evidence relating to Personal Independence Payment (PIP), housing benefit, Job Seekers Allowance and the Independent Living Fund. We also wanted to evidence how the changes to charging for social care were impacting on services people received.

The diarists were from a range of impairment groups. We were particularly keen to include questions that gauge the impact of the cuts on mental health and well-being. We set up a dedicated Facebook page to regularly provide news updates, reports and articles and we received an average of 20 posts per month.

Some of the people involved in the campaign have become volunteers at SPECTRUM and one has become a SPECTRUM employee. A number of people have expressed an interest in further involvement with the organisation, an example being a campaign strategy group.

Hampshire Cuts Campaign

By Berni Vincent & Gerry Zarb

Impact of the cuts:

Many people told us about the cuts to services impacting their ability to use community facilities or not having the assistance needed to support family or leisure activities.

There was strong evidence that the cuts to services are having a real impact on people's ability to lead quality lifestyles that are free from stress and anxiety. People routinely talked about feeling lonely and depressed and fearful of opening their post for fear of hearing more bad news. People were fearful of the future and felt there was a real risk of having even less choice and control in their lives.

Perhaps the most worrying part of our findings concerns the impact on Disabled People's health and well-being – especially their mental health. Our research diaries included a module of standardised questions used by some of the leading national debt charities to alert advisors to cases where people should be advised that they are likely to be at risk of serious mental health problems.

Key feedback from the diaries included:

- Severe financial difficulties, with many people regularly going without food or other essential items.
- Concerns about changes in eligibility for Employment Support Allowance (ESA).
- Cuts to local authority support packages, leading to strain on both Disabled People and their families, with some people frequently being left in very vulnerable situations.
- An increase in social isolation and exclusion resulting from lack of support and/or money.
- The extremely negative impact on both physical and especially mental health.
- The impact of cuts to community facilities and other public services, including libraries and transport services, was also evident.

Hampshire Cuts Campaign

Continued

Some quotes from the diaries:

“My friend provides support with helping me in and out of the bath. He can only come once a week as he works so I’m reduced to having a bath once a week now.”

“I get 12 hours a week to cover the absolute basics like personal care. There is never enough so my family help me.”

“The standard of interrogation from the direct payments has gone from an encouraging chat about how it’s going to ‘how many hours do you REALLY need?’”

“I rely on my friends to access the community. If they are not available I cannot go to the cinema, access the arts. This is one of my favourite things without this life is not worth living and is grey. This helps my depression.”

“My main care and support - social and emotional - is missing from my life. I don’t go out and I don’t visit friends.”

“It’s every day, all the time. Sometimes I feel like I want to jump off a building and sometimes I cry when I’m on the phone dealing with my benefits. All the time I feel depressed. I constantly think about what will happen next.”

“Even if I’m well I feel anxious. I feel trapped and snowed under.”

Hampshire Cuts Campaign

Continued

Where the campaign goes from here:

SPECTRUM Staff and Management Committee are currently in the process of deciding the future of the campaign. Limited resources and staff capacity obviously impacts on future work carried out on the project. We want to find ways of working with other allies, partners and others working to raise awareness of the impact of the cuts, including SENDPO, the Personalisation Expert Panel (PEP) in Hampshire and Consult & Challenge in Southampton.

It is vital that we make best use of our networks and connections to work together and disseminate findings. We also hope to use social media, write press releases and utilise local radio.

Everything we say will be based on evidence and reasoned argument. The emphasis will be on highlighting the real impact on Disabled People's lives. We do not intend to be aggressive or sensationalist, although we do want to emphasise the seriousness of the situation and why it is unfair.

Some of the key messages we want to get across are:

- Far from living it up at the taxpayer's expense, many Disabled People were living at close to poverty levels even before the cuts. There is plenty of authoritative evidence for this, including from Government data sources. The cuts have simply pushed people over the financial cliff edge.
- The impact of cuts to benefits and services is cumulative and, taken together, can have extremely negative consequences for people's ability to have any sort of life at all.
- The risks of social isolation and exclusion are greatly increased as a result of the cuts and this not only has costs for Disabled People themselves but also for the rest of society (e.g. by making people even more detached from the labour market which, ultimately, increases the welfare bill and, by increasing mental and physical health problems, adds to the costs for the NHS etc)
- While the situation is already serious, there is much more to come as some of the cuts are still to be fully implemented. While it may not be realistic to expect any reversal of cuts already made (in the short term at least), there is a strong case to be made for reviewing cuts that are planned for the future.

Hampshire Cuts Campaign

Continued

Conclusions:

SPECTRUM is indebted to the people that gave up their time to contribute to the cuts campaign. For the majority of people, evidence shows the serious impact to independence, inclusion and quality of life. It is even more unfair that Disabled People are taking a bigger hit from the cuts than any other group in society.

A recent report by the **Centre for Welfare Reform** found that Disabled People, who make up 8% of the population, are being hit by a massive 29% of all cuts being implemented. This cannot be allowed to continue at its current rate. SPECTRUM with our partners and networks will continue to do our best in raising this issue and addressing the cuts.

Worryingly, the media is not always highlighting the issues and protests that are coordinated by dedicated groups throughout the country. So many Disabled People feel that nothing is being done and the issues are not being raised.

SPECTRUM will continue to provide updates through our social media platforms and newsletter on the future of the campaign.

SPECTRUM offer placements to students

Jeff Downing

Any reader of this article may well be surprised by hearing my first response to the idea that SPECTRUM Centre for Independent Living, should set up a Social Work Student unit. I can recall that I laughed at the very idea and actually rejected it out of hand.

My reasoning at the time was two-fold. I felt that any student attending placement at SPECTRUM would learn how to become more eloquent in using the language of equality to oppress Disabled People and my second reason was based on the financial contribution we would receive for having students on placement.

Now the above view was not just because I am a Disabled Person, but perhaps more surprisingly, I am a Qualified Social Worker and Practise Tutor, meaning I already had a significant part of the skills and experience to run the unit, so why did I just laugh? Well, the main reason was my reservations on what this venture could do to the organisation, which was already facing some controversial challenges. However, time is a great healer, or so someone said and this has proved to be the case here.

As I write this report for our special anniversary issue, I am preparing for our September intake of social work students. As the academic year runs from September to June, we generally have two intakes of students. The September placement is made up of students on their final placement before they qualify in July and start their job search.

The level five students usually move into their first placement in January and so in the Spring of 2015, we will have students on placement from both Solent and Portsmouth Universities, either on their first or final placement. The first intake is with us for 100 days and the second for 75 days.

To date, we have had 62 students pass through our unit but not all have passed their placements and I have failed about 10 for one reason or another. Failing a student is quite a complex process and is only taken after very serious consideration and soul searching on the part of the teaching team. However, failing a placement is a bit like failing a driving test, you can always have another go, providing you do not injure or kill the instructor. However, the key point here is that all who wish to practice social work, should not always be encouraged to do so in my humble opinion.

The Student Unit

Continued

So what do these budding social workers do on placement? One of their very first introductions is a large red button that sits on my desk. I use it during formal supervision with students and it has a number of ways if pressed of saying "that is but....dddddt". Once they are used to my Northern Wit, plain speaking, honesty and dislike of but....dddddt, we generally get on well. Just to reassure the reader, the students do get an opportunity to talk about me at the end of their placement to Ian Loynes, the big cheese, so they do get their own back!

A key social work skill and role is that of being an advocate for the service users they are supporting. We are therefore able to offer the student plenty of advocacy work supporting Disabled People in a wide range of issues: housing, employment, discrimination issues and disputes with the local authority in relation to Adult Social Care provision. This gives the student the opportunity to see what it is like for those of us who live on the other side of the fence. Many of the students are frankly, appalled by the poor professional communication they experience on placement. So if they find it frustrating to sit at a desk and wait for the statutory agencies to return their calls, emails and letters, they can hopefully appreciate what the service users' experience. This real life experience, as opposed to the theory of social work and their sometimes idealistic view of state services and intervention, can very often be sharp learning curves for the younger student.

All students on placement undertake a project role and this could be quite complex and involve a lot of planning and the ability to allocate roles and tasks. In fact, this particular role on placement is not unlike the tasks that Lord Sugar gets his apprentices to undertake on the TV show The Apprentice, but unfortunately, or fortunately for student social workers, I do not get to fire them!

The final task they undertake is usually that of a mentoring Disabled Person, through empowerment, to achieve a particular goal or task. This could be in relation to learning new skills, such as word processing or undertaking a new volunteering role both internally and externally.

So you can see, these poor students are kept busy and have a lot to put up with and I am a hard task master, but fair; I am seen as a nice teddy bear by some and a fire breathing dragon by others, it just depends on your point of view. My job is not to help train statutory social workers of the future, as in reality the social work qualification can open many doors and students need to consider job satisfaction and see beyond the state sector, which may not always be the ideal job for the social work student.

SPECTRUM Support new & evolving ULO's

By Steve Boswell

This project was set up in September 2012, in conjunction with Hampshire County Council's Adult Services, and is aimed at encouraging the formation, development and sustainability of user and community-led organisations. These are groups that are run by and for themselves, rather than by any outside organisation. They may be made up of groups such as Disabled People, whether they have physical, sensory or other impairments, Older People and Carers and from any of Hampshire's diverse communities. The initiative has to be inclusive, involving people from Black and Minority Ethnic, Gypsy and Traveller or Lesbian, Gay, Bisexual or Trans-sexual communities among others. What they will all have in common, however, is that they are run in order to represent their own interests and needs. Assistance offered by the ULO project can range from suggesting funding sources through providing training on Social Media and commissioning up to creating an organisation that is fully legally constituted like SPECTRUM.

Parability, founded by Chris Hall in Basingstoke, runs a monthly Activities and Social Group, for example providing light seated exercise with a qualified coach. It is a great example of what the project has been able to, and hopes to continue to achieve. Chris first came to a couple of our launch events and these were then followed up by face-to-face meetings and mentoring on how to approach the development of Parability. Roger Fenn, Ian Loynes and Lesley Long-Price were able to provide him with help and guidance, and also



supported him as he built relationships with the local Council and other interested groups. "SPECTRUM helped Parability link up with Basingstoke and Deane Borough Council, The Cafe Project & Hampshire Wellbeing Services. These links in turn helped us establish the Parability Activity and Social Group and has led to us linking up with South Ham Direct" said Chris.

Support new & evolving ULO's

Continued

We continue to provide on-going support, both in terms of training and also helping to design and print Parability's flyers, sending their advertising around our contacts and providing help and advice. Chris maintains that "SPECTRUM's training has helped Parability extend its Social Media reach and its events have allowed us to network with other organisations".

Parability exemplifies the sort of hands-on support that we can provide for user and community-led groups. Below are some of the ways in which this is available to anyone who needs a helping-hand from us.

- Advising, guiding and mentoring groups to help them develop, thrive and, should they wish to, work with the Council in developing policies such as their commissioning of services: we can provide this advice by e-mail, over the phone or by face-to-face meetings and can cover help obtaining funding, putting groups in touch with each other and how to run an organisation more effectively. We ran the Home Care Competition, aimed at finding the best ideas for user-designed Home Care in Hampshire, and provided mentoring support for the entrants and are still doing so for the winners (see separate article).
- Providing training: we've run a series of training courses here at SPECTRUM on the things that current and prospective groups have said that they needed.
 - Social Media
 - Funding your organisation.
 - Becoming legally constituted: a Community Interest Company like SPECTRUM, a Charitable Incorporated Organisation or a Co-operative.

These are the courses that we have organised so far but if there is enough interest we can try and repeat these, set up others or sign-post people to those being run by different organisations. The courses are run free of charge and we pay reasonable expenses.

- Networking: we maintain a database of contacts from all our target groups that allows them to find out who else around Hampshire might be interested in talking to them. The ability to interact like this helps people to share ideas, experiences and expertise. This is all supported by our bi-monthly newsletter that lets people know what the project and its contacts are doing, advertising their events and training going on around the county.

Support new & evolving ULO's

Continued

- Website, Facebook and Twitter: our website provides updates on what we have been doing and sources of funding available to user and community-led groups, along with pages advertising events and training. The External Events page is open to anyone who wants us to publicise their event to a wider audience.

The website also contains a suite of pages providing guidance notes on areas such as Obtaining Funding, Social Media and Campaigning. The notes have come from a variety of sources involved in working with and advising different groups, so Gerry Zarb, the Project's Policy and Information Officer, has provided introductions to each one so that people can choose which one may be most relevant to them and their stage of development.

Our Facebook and Twitter accounts allow us and other groups to exchange ideas and publicise what is going on.

- Organising and supporting events: we worked with the Hampshire Independent Equality Forum with support from Hampshire County Council's Inclusion and Engagement Team to organise the Council's extremely successful Community Mixer on June 11th 2014. This was aimed at promoting networking between all the organisations there and to inform communities of the various funding options available. In addition to the talks and stalls, there were a couple of sessions where people had a three minute slot to talk about their organisation and what it does, providing a wonderful opportunity for everyone to get the chance to find out who was there and so creating the opportunity for groups to network.

We were asked to be on the organising committee of the Fareham and Gosport Multi-cultural Society's first major event in Gosport earlier this



summer. We were able to not only provide them with advice but also print some flyers for them and advertise the event on our website, Facebook page and via Twitter. The event included a mix of various cultural and more familiar entertainments, with stalls selling ethnic cuisine and crafts and supporting organisations, such as ourselves.

Support new & evolving ULO's

Continued

At the time of writing, we are organising a conference on Hate Crime. We are bringing together members of groups who are affected by this, for example Disabled People and the Black and Minority Ethnic and Lesbian, Gay, Bisexual and Trans-sexual communities, along with representatives of a range of Public Bodies (e.g. Hampshire Constabulary and Local Community Safety Partnerships) This will allow the affected groups, through a mixture of talks and workshops, to describe the problems that they face, both those in common with other groups and those that may be community-specific. This should allow the two groups, victims and the responsible authorities, to formulate an Action Plan that they can take away and use as the basis for addressing the problem of Hate Crime in our communities.

To date, we are already achieving a large amount of what the project was designed to do. With the help and advice that we have been able to provide through e-mails, phone, meetings and our website, we have helped develop User-Led Organisations like Parability and Capable Creatures towards being constituted. We have been able to help develop User-Led Organisations like Chatterbox through our training and Disabled People's Voice Hampshire through mentoring in the Home Care competition. We have also developed another of our main aims, enabling some groups to be able to work with Hampshire County Council in helping shape their policies. We have also enabled groups to network through our range of contacts and events.

If you are interested in finding out more about the ULO Project then please contact us:

E-mail: ulo@spectrumcil.co.uk

Telephone: Roger Fenn on 02380 202937

Or visit our website at: www.spectrumcil.co.uk/ulo/

The ULO team are Stephen Boswell, Gerry Zarb, Roger Fenn and Jennie Musson.

SPECTRUM & Co-production - Service User-Designed Commissioning

SPECTRUM Centre for Independent Living CIC and Hampshire County Council: Service user-designed commissioning.

Key themes:

- Co-production and service user designed commissioning in action
- DPULOs and local authorities working together to make the commissioning process more accessible for new and emerging ULOs
- Developing the market and increasing local choice by creating capacity building opportunities for new and emerging ULOs
- Commissioning services which achieve user-designed outcomes more effectively
- New approaches to commissioning (e.g. user-driven commissioning) which change the culture of service provision and involve DPULOs as essential partners

At a time when co-production is acknowledged as the best way forward for service provision, this presents a valuable opportunity for local authorities to support service users to design their own services. SENDPO talked to Gerry Zarb, Policy and Information Officer (ULO Team) at SPECTRUM, about why Hampshire County Council and SPECTRUM decided to run a competition to find the best ideas for user-designed Home Care in Hampshire and what they have learnt from the process.



Scoping and funding the competition:

'Basically two things went into this idea: the first was that, in the last couple of years, Hampshire County Council developed a new commissioning strategy which builds opportunities for user involvement into every stage of the process, from designing services right through to the selection of contractors; secondly, we discovered that in 2014 the main priority for commissioning social care in Hampshire will be Home Care services or care at home, if you prefer, which is obviously a service that is very important to a lot of disabled people, older people and other user groups. Combining these two things presented **a very good opportunity to do some work on trying to put co-production and service user-designed commissioning into practice.** So, we came up with the idea of this competition.'

Service User-Designed Commissioning

Continued

'It was designed in a way which would encourage people to get involved and do something a little bit different. I also felt it was important that, if users were going to come up with something as important as a design for a new Home Care service, that they should get some real material reward for that in the form of actual funding. It was open to all groups, large and small. We were particularly keen to encourage partnership working between smaller groups or individuals, maybe working with a more established group who might be able to support them. We had a good mix of groups who entered the competition: a couple of groups of older people, some Disabled People's organisations, people with learning difficulties and groups with memberships across different user groups. You didn't need to be a service provider to be involved in the competition, to know anything about commissioning or to have any special skills or experience. The only thing we wanted was people's good ideas.'

'Hampshire County Council also gave grants to groups developing their ideas to cover the costs of holding meetings, travel expenses, consulting with their users, or to carry out research, etc.; these grants were very important especially for smaller groups who might not have been able to participate without that funding. **Groups participating also had one-to-one support and advice from SPECTRUM and we tried to advise people on the best way to package their ideas and present them in a way which makes them attractive to commissioners in the Council because, as those of us who have dealt with commissioners know, they don't necessarily speak the same language as the rest of the population!** The plan was to award a cash prize of £5,000 development funding for the winning idea so that the group could develop its ideas further and use it for anything related to commissioning or user-led service design.'

Selecting a winner:

'Finding a winner was slightly trickier than anticipated as the judging panel was split between two of the entries, both of which scored highly. In the end the Director of Adult Services at the Council (who had a casting vote) decided to top up the prize fund and split it equally amongst both groups – one of which was a DPULO and the other an Older People's organisation. The two winning entries were from Disabled People's Voice Hampshire and Local Treasures.'

Service User-Designed Commissioning Continued

Quotes:

'Disabled People's Voice Hampshire's proposal clearly identifies a need and a gap in supply. It could make a significant contribution to extending the take-up of Direct Payments. It could also support people in rural communities where there is a shortage of paid carers.'

Home Care Competition Judging Panel

'Distinctive – The Treasures are peers (Older People) and there is a positive focus on early intervention and reduction in social isolation for Older People.'

Home Care Competition Judging Panel

'Disabled People's Voice Hampshire's proposal was for a website-based service to help users find personal assistants, who not only can meet their care and support needs, but also have similar interests, life styles and personality types. This could also include the profiles of agency staff, for people who are not employing their own personal assistants.'

'Local Treasures, based in Petersfield, was set up in 2013 and involves older people providing other older people with support in and around people's homes, with jobs such as gardening, cleaning, cooking, DIY, decorating, shopping, giving car lifts, etc. All of the work is done by people aged over fifty and it taps into the skills and experience of a robust, willing and confident workforce. Their proposal outlined their ideas about how this kind of support could be extended across the county.'

'So, in the end, we had two winners instead of one! That's two sets of ideas that can be developed further for the benefit of commissioners and, just as important, two groups that have the opportunity to speed up their development and capacity building. Also, from the perspective of our broader objective of developing ULOs, it is particularly pleasing that the two winners are the two newest groups who entered the competition – both have only been going a year or less. Each of the winners has received £4,000 of development funding, plus one-to-one mentoring from the Deputy Director of Adult Services to help them develop their ideas further, to build their capacity, skills and knowledge, and, hopefully, move towards a position where they are able to tender when the Council starts its commissioning tender next year.'

Service User-Designed Commissioning Continued

'The entries that did not win will all be provided with signposting support to explore how their ideas can be developed further. We will also continue to offer one-to-one support to other groups who took part, if they want it. For example, we have already been talking to one of them about how they might take advantage of the Council's priorities for commissioning in 2015, which is an area in which they already have some expertise so, if they can build their capacity, they could be in a position to tender next year.'

Impact of the competition:

We asked Gerry what the benefits were of having a competition like this:

'All of the good ideas, not just the winning ones, will feed directly into Hampshire's commissioning plans for 2014. **It is a real opportunity to shape a local service across a large county in south-east England and improve outcomes for users.** We also sold the idea as a way of helping ULOs to build up their sustainability and develop new contacts, both with other user groups and with the Council, as well as learning more about the commissioning process itself and the benefits of getting involved. Also it is an opportunity to demonstrate how user-led organisations bring added value to service user-designed commissioning and what they offer that perhaps some of the larger service providers cannot. **But I think the most important benefit is that it is a real life example of co-production in action. What we are trying to do is to turn the rhetoric about user-controlled commissioning and service design into a practical reality in Hampshire.'**

'We made entering the competition as simple as possible, only requiring a brief description of ideas with a few bullet points. We asked people how they would maximise choice, control and buying power for users of Home Care services, including people who pay for their own care rather than being supported by the Council.'

'We also asked for ideas about producing the outcomes that users want and that can be built into the contracts, so that contractors will be accountable to outcomes defined by users themselves. We asked people about their ideas on monitoring the quality of support that is provided and, lastly but probably most importantly, **people needed to say how users would be involved in developing their ideas** for an ideal Home Care service.'

Service User-Designed Commissioning Continued

Some findings:

‘One of the issues we initially identified in our networking was that many DPULOs (both large and small, but especially small) think that commissioning is too difficult to engage with and that they don’t really understand it – they think the option of being able to influence the process is beyond their scope. So, through this competition, we were able to show that, **if you repackage the issues and processes into a different format and if you use language that makes sense from a user perspective, people soon discover that there is, in fact, plenty of scope to engage in a meaningful way.** We have shown that commissioners working in partnership with DPULOs can make this happen fairly easily, if the will is there.’

‘Another of our objectives has been to build the capacity of ULOs, as a way of trying to level the playing field in terms of being able to compete in the new commissioning landscape. **Part of this has involved working with the Council to simplify some of the processes involved (like application forms) to make them more accessible.** This is a benefit to all DPULOs as we know that even the larger groups often struggle with the bureaucracy, if for no other reason than it is so time-consuming! However, although we produced a simplified version of the standard Small Grants application form, feedback received from some groups was that the application process was still too time-consuming and involved too much paperwork. It was felt that this might have discouraged some groups from participating. So **there is clearly a learning point about the need to make sure that support and advice is available to help build the capacity needed to engage with such funding processes,** and that is something the Council is going to look at.’

‘The benefits of having access to one-to-one support and advice was demonstrated during the main stage of the competition as **the support we were able to give some of the smaller DPULOs in particular has increased their level of confidence and knowledge to the point where, in some cases, they have already been able to start planning how they can use commissioning opportunities in the future to help them become more sustainable.** As a larger DPULO, we have also developed our own capacity and expertise by being involved in this process and have identified potential for new income generating products as a result. Hopefully other DPULOs might see similar potential in their own areas.’

Service User-Designed Commissioning Continued

‘At the same time it is probably no coincidence that the groups who chose not to take up the offer of advisory support fared worst in the competition. In one or two cases, groups did share their draft plans and request feedback but only at the last minute, which obviously limited the amount of support we were able to give. So, we need to think about how we can encourage organisations to accept support when it is offered. In any case, it is very clear that **more intensive support, advice or mentoring is required to enable ULOs and community groups to maximise the potential of their ideas for service design.** Also, even though time and support were made available, the process still highlighted significant gaps in capacity: while several of the ideas submitted were genuinely innovative, the quality of the proposals in terms of presentation and detail was such that participants would probably not be successful in a real time tendering environment. So, in order to help build capacity, we will now be looking to coproduce training resources for ULOs and community groups which will help to increase capacity in a sustainable way over the longer term.’

‘**This process has also highlighted the benefits of networking, which is a central focus throughout our ULO project work.** Some of the smaller groups participating in the Home Care competition are groups with whom we had no previous contact. So this has helped to extend the network, which has been good for them as building new contacts is one of the things they say they need and want to do, but also for larger ULOs, such as ourselves, because it means we have new potential partnerships. We are, for example, already working with one of them on a bid for some other work on a partnership basis.’

Resources:

<https://www.facebook.com/DisabledPeoplesVoiceHampshire/timeline>

<http://www.local-treasures.co.uk/>

Article reproduced from, ‘Confident Commissioning. Building relationships between local authorities and Disabled People’s User-Led Organisations’. SENDPO, June 2014

Please see over the page for follow-up Guardian Article by Peter Beresford.....

Guardian Article, Wednesday 19 February

By Peter Beresford, Brunel University

Hampshire competition paves the way for innovative approaches to homecare

Remember when homecare was a respected realm for multi-professional, community-based help and support? Sadly today, debate about homecare has largely been overtaken by a focus on the problems besetting the service.



Workers report the burgeoning of zero hours contracts, and raise concerns about being tied to sub 15-minute visits and real pay that's less than the minimum wage – because time isn't allowed for travel, training or supervision. On the receiving end, disabled and older people talk of a succession of anonymous strangers coming through their door, arbitrary restrictions on the tasks they are allowed to do and the lack of respect, privacy, dignity and kindness in the way such work is carried out.

All this can be seen as a further expression of the political devaluing, under-funding and neglect of social care in England. Yet social care is also a policy area where some of the most innovative, grassroots developments appear to be taking place. Sometimes, of course, this is more a matter of rhetoric masking reality. But the emergence of disabled people's and user-led organisations and the increasing involvement of service users in professional training, planning, commissioning and practice development, are expressions of a will for something different – a true evocation of personalisation or "person-centred" support.

In November, a conference in Hampshire brought together commissioners and service users and their organisations, to share learning and take forward work on "user-driven" commissioning. Their aim was to share experience and learning from local initiatives in several counties – all of which highlighted the real gains of matching support with people's needs, by pooling direct payments and involving service users and grassroots providers. It highlighted the real value of a "corner shop" as opposed to a supermarket approach to the social care market – while highlighting that the present direction of travel seems, unfortunately, to be in the opposite direction.

In this same spirit of "co-production", Hampshire County Council and the disabled people's organisation SPECTRUM, jointly organised a competition to develop innovative approaches to homecare.

Guardian Article

Continued

Like many other health and welfare buzzwords of the early 21st century, "co-production" has been the victim of over-use, ill-definition and deliberate misuse. But here was an example of the idea as it is meant to be, involving real efforts to increase equality and co-operation between local services and local service users and their organisations.

Seven local user-led organisations responded to Hampshire's invitation to develop a proposal, each receiving some funding support and independent guidance and expertise to help them with their bid. This resulted in five fully worked-up bids being entered for the competition. The ideas ranged from a user-led training scheme, to a loyalty card and a 24/7 free information call-line. The proposals also included a smart technology linked to people's homes to provide virtual visits, non-intrusive advice and support – and where needed home visits, and a person-centred scheme prioritising user involvement and an enhanced choice of carers.

Judging was by a mixed team of Disabled People, service users and staff from Hampshire adult services. There were two joint winners: the first, developed by Disabled People's Voice Hampshire, is a web-based service to help people find reliable personal assistants and support staff who closely match their unique needs and preferences.



The second, Local Treasures, offers a network of over 50-year-olds to provide home help to support older people in maintaining their independence and wellbeing. This offered employment opportunities to older people, as well as all kinds of practical support.

The joint winners will receive £4,000 each to take their ideas forward.

Hampshire's homecare competition suggests that a real route to innovation is from the "bottom-up". But it is also a timely reminder that the social care market offers much less than a level playing field to small user-led, community-based and black and minority ethnic organisations. Yet, because of their local knowledge, shared experience and closeness to people's issues, these grassroots groups have some of the best ideas and responses to offer.

SPECTRUM & Co-production - The Personalisation Expert Panel (PEP)

SPECTRUM Centre for Independent Living CIC and Hampshire County Council: Strategic investment – the Personalisation Expert Panel (PEP)

Key themes:

- Strategic investment in a DPULO to help a local authority achieve its corporate objectives around personalisation
- A partnership of equals, creating the optimum conditions for co-production and facilitating a cultural shift in commissioning practices
- Raising the profile of, and building the capacity of, new and emerging ULOs by enabling networking and dialogue with commissioners

Hampshire's Personalisation Expert Panel is run by SPECTRUM, a well-established DPULO with a strong infrastructure (it is the only south-east DPULO that self assesses itself as meeting the full 28 ULO design criteria). Local authority investment in this strategic initiative is a testimony to the strong, long-term working relationship between Hampshire County Council and SPECTRUM.

SENDPO talked to Robert Droy, Chair of the Hampshire Personalisation Expert Panel, about its background, challenges and successes.



The Personalisation Expert Panel (PEP)

Continued

The background:

'In 2008, Hampshire County Council (HCC) initiated a 'Commission on Personalisation' to look at how adult social care would be delivered over the next five to ten years. Apart from Peter Beresford, Chair of Shaping Our Lives (the national organisation and network of disabled people and service users), there were no other disabled representatives from local or regional Disabled People's Organisations (DPOs), including SPECTRUM (then Southampton CIL), involved. Because of this, DPOs were quite cynical about the initiative as we felt excluded from discussions about us: it felt very 'top down' rather than 'bottom up' and created a bit of a gulf between Hampshire County Council and DPOs and ULOs. However, Hampshire County Council soon realised that DPOs should have been involved from the beginning. So SPECTRUM and the Hampshire Centre for Independent Living made an alternative proposal to **Hampshire County Council to set up a panel of experts from different organisations – we asked for funding and a commitment from Hampshire County Council to come to the Panel on a regular basis, with a view to working co-productively.**

The Head of Social Care wanted to promote a more collaborative way of working so Hampshire County Council agreed to fund the panel initially to meet every three months but, as there was so much to discuss, this changed to monthly.'

Membership and funding:

'Currently the PEP consists of a core group of eight to ten people and others that come and go. Hampshire County Council staff are not actual members of the Panel – they come to listen and input their opinions on matters being discussed. Member organisations include SPECTRUM, Hampshire CIL, Carers Together, All Inclusive (a Hampshire-based training consultancy) and a number of independent service users. Previously we have also had representatives from the Learning Disability Partnership Board and RAISE, a user-led mental health organisation, but membership and attendance does vary. SPECTRUM receives about £16,000 per year to be the secretariat, chair the meetings, cover room hire, refreshments and other expenses, such as travel, as well as attendance fees for Panel members (£60 per 3.5-hour meeting). The budget does get gobbled up quite quickly as we are a large county! We also organise an annual conference for Disabled People and carers, with workshops on current issues; for example, the last time the Law Commission did a workshop on adult care reform.'

The Personalisation Expert Panel (PEP)

Continued

Aims and remit of the PEP:

'The PEP aims to ensure that Disabled People are involved in every aspect of adult social care, in designing, implementing, delivering and evaluating services. Every new 'personalisation initiative' is usually discussed with the panel as well. **It's much more than consultation – it's about being round the table when Hampshire County Council is thinking about getting a project off the ground, the whole way through and not just at the last minute. It should be 'true co-production'.** Discussing new initiatives with the PEP is pretty much engrained now with Hampshire County Council senior management. As the PEP has limited capacity, we cannot engage on everything and sometimes we have to prioritise what we think is most important to influence. Recently, for example, we prioritised work around personal budgets.' 'I set the agenda, after talking to Panel members and Hampshire County Council staff about what projects are going on. Hampshire County Council is good at bringing ideas for projects to the Panel which it knows the members will be interested in discussing, and contributing to the development of, before they start. Some examples include the paperwork around personalisation and helping to develop self-directed support training for care managers.'

'We also invite different guest speakers along to tell us about projects they are working on which will be of interest to the PEP and we discuss how the PEP could support them in the future; for example, we recently hosted **the new Chair of the Safeguarding Board, which has an active service user forum. We keep an eye on policy development and think about how national agendas will impact on Hampshire; for example, we did some work with the Cabinet Office on the Big Society and we ran some workshops around health care reform and CCGs (Clinical Commissioning Groups), the Health & Social Care Bill and welfare reform and how all this applies to Hampshire. It is a very strategic approach.'**

Quote: 'For me, the PEP is a reference point for our management team to know what we need to take into account for our strategies. Our commissioning process has strong user involvement and the PEP has helped us to get there: as far as Disabled People are concerned, it represents high quality engagement.'

**Ed Walton, Senior Community
Development Officer (Service User
Involvement), Hampshire County Council**

The Personalisation Expert Panel (PEP)

Continued

'It's important that SPECTRUM chairs the PEP. **It must be led by a DPO. Our experience and expertise give us gravitas and we are a role-model for a lot of Disabled People – that's the reality, and it is a powerful message for me to be chairing the PEP, rather than Gill Duncan, the Director of Adult Services.** The PEP feels very different from traditional local authority service user forums – often these are run by local authority staff who set the agenda and don't even share the material in advance; service users have no influence over and it is little more than a rubber-stamping exercise. **With the PEP, however, although Hampshire County Council has some influence in terms of what we discuss – an essential part of coproduction – Hampshire County Council certainly doesn't dictate the agenda.'**

Challenges

'**The PEP has helped Hampshire County Council to understand DPOs and the challenges and sometimes there are conflicting agendas. But we also appreciate that Hampshire County Council has to meet the demands of government agendas, as well as manage a tough financial climate.** Hampshire County Council has gone from being fairly well off to having to make substantial cuts. This did cause a problem for the PEP when Hampshire County Council decided to review its charging policy. We couldn't engage with this – **it was so contrary to SPECTRUM's principles that we couldn't compromise** and we didn't want to be seen as approving, so we had to pull out from that process. Hampshire County Council, however, understood the difficulty of us supporting a policy change which could be detrimental to Disabled People and didn't put barriers up in terms of us engaging on other matters, which we felt was a mature response.'

'We are involved in influencing commissioning policy but not in actually making commissioning decisions. For example, we have worked with Hampshire County Council on its procurement practices and its category management; rather than commissioning nearly two hundred individual services separately, Hampshire County Council has now grouped different services together into similar or related products, known as 'product categories', which will hopefully result in more holistic services (and about forty contracts overall). However, this way of working could present a bigger challenge for smaller DPOs trying to win contracts so they may need to get together and bid for contracts as partnerships. We need ways to link them together and it's possible in the future that the PEP, as a coordinator and facilitator, could bring ULOs together to bid for work. We also need to look at how ULOs can be more involved in helping to draft service specifications.'

The Personalisation Expert Panel (PEP)

Continued

Leadership:

'In many ways our success is down to our relationships with local authority staff. Individual leadership is crucial and Gill Duncan, the Director of Adult Services, is totally committed to the principles of personalisation. **It is vital to embed the right approach into policy and procedure but it is still fundamental to have staff with the right attitude. Unfortunately, if staff are not committed at the top, after a while they will simply stop coming to meetings and stop engaging, even if the policy is right.** I know this has happened in other areas. There are times when our PEP can feel a bit tokenistic as some people who come aren't very interested. Of course, staff will be naturally defensive if their policy is criticised but we have to focus on making people understand that we genuinely want to try to help them to do a better job. **Trust is essential and Hampshire County Council staff trust that the PEP will do the right thing; they view the PEP as a critical friend and, while we may sometimes be confrontational, they know we will not deliberately cause problems.'**

Successes:

'We have had some PEP successes. For example, we had to look at the issue of personal budgets, known as self-directed support in Hampshire County Council. Frontline practitioners didn't really understand why they were doing it. They needed training to understand the importance of looking at the whole person and not just the impairment. So, a couple of PEP members, who are also service users, co-delivered training with the Council to social workers, staff from day centres and other healthcare providers. We wanted to encourage them to get their clients interested in personal budgets and this training has helped them to understand the importance of doing an assessment in the right way, making the process much less of a tickbox approach.'

The Personalisation Expert Panel (PEP) Continued

What would happen if the PEP ceased to exist?

‘Without the PEP we would start to lose the service user voice. We need to think about the possibility that the PEP may not exist in the future, if policy changes in the local authority, and we need to think about alternative ways of keeping the good work going. The most important thing is to maintain positive relationships with Hampshire County Council, especially when the financial situation is so critical. The cuts will affect some Disabled People very badly – some will only have minimal support to get up in the morning and go to bed and it shouldn’t just be about feeding and watering people! If there is no money for services, what will the PEP do?’

Resources:

For further details about Hampshire’s PEP visit:

- <http://www.spectrumcil.co.uk/getting-involved/personalisation/>
- Watch the following video: <http://www.scie.org.uk/publications/guides/guide36/video/sustaining.asp>

Article reproduced from, ‘Confident Commissioning. Building relationships between local authorities and Disabled People’s User-Led Organisations’. SENDPO, June 2014

SPECTRUM & Co-production - Consult & Challenge

By Will Rosie



The last year for Consult & Challenge has seen the group go from strength to strength. For those of you who don't know, the group evolved from the old Southampton Overview Group and has been able to continue with funding from the now closed Care Assessment Framework for Adults II programme. We are a coproduction group working primarily within the boundaries of Southampton City, in order to build equal working relationships between service users and service providers. In layperson's terms this means 'Service users getting over the 'chips on their shoulders, service professionals getting over the title on their badges, and together using their individual expertise to generate the best results!'

Considered 'local experts' or 'experts by experience', we engage and work with those public servants tasked with the healthy and effective running of the city. Our distinctive diversity, and friendly yet focussed attitude, provides an effective platform to work from, as we continue to build healthy relationships with the major city stakeholders.

The past year has seen the group grow both in terms of numbers and also diversity, making us even more representative of the Southampton communities. Although the project was intended to be budgeted for a year, careful use of the funding and an extra boost from further commissioned work will see us safely into the new financial year. Because of the increasing expertise and experience of the group we are readily becoming a group that is funded not by a hand-out, but by commissioning of the skills we have to offer.

Consult & Challenge Continued

You might remember earlier on this year, that we were called upon to help Southampton City Council with the development of the City's new online portal. Well, the group have thrown themselves into the task, and have produced the bulk of buttons that visitors to the portal will use to navigate their way to the right destination, and to pick up the right kind of information along the way. We are just about to start meetings with the portal developers to see how our ideas can be made real, so watch this space!

Would you like to join our coproduction team? If you are a Southampton resident who is either a Disabled Person living with an impairment or caring for someone, then we want to hear from you.

Consult & Challenge has a monthly group meeting, as well as several working groups depending on how many 'live' projects we have going on.

If you want find out more about how to become a member of Consult & Challenge, or are interested in getting more information, please call Will Rosie on 023 80202632 or email will.rosie@spectrumcil.co.uk



The battle for the Elephant and Castle (July 28 1988)

We were sisters and brothers
and a whole bunch of others
not to mention a long line of blue
we were disabled, united
and completely incited
by an anger we knew to be true
we were 2000 strong
and a half mile long
as we marched to the Elephant and Castle

with no sight or no hearing
a kaleidoscope careering
filling the sky with our voices
we marched down the street
to tell the elite
we demand a world with new choices
we had in our sights
a blow for our rights
as we marched to the Elephant and Castle

we were at the beginning
of a new way of winning
together we could not be denied
so we strolled up and down
in old London town
wearing our badges with pride
we fought the law
and we'll fight it some more
at every Elephant and Castle

By Simon Brisenden, founding member of SPECTRUM



Centre for
Independent
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Celebrating
30 years of choice
and control



Think you know
Disabled People...Think again



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