Welcome to the new digital version of our newsletter. Due to rising print and postage costs we have decided to produce a digital newsletter. **Shaping Our Lives understands that not everyone can access digital versions, so we are offering a print version on request.** This will be photo copied rather than printed.

One of the benefits of going digital is that much information is available through internet links so we can now signpost our members to relevant topics and articles of interest available through the internet.

If you require a photocopied version please email information@shapingourlives.org.uk

Or by post to:

**Shaping Our Lives**

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Gerry Zarb, Business Development and Policy Manager, SPECTRUM CIL

The Care Act 2014 updates and combines all the various care and support legislation into a single act. It also introduces some new duties for local authorities, including a duty to consider the physical, mental and emotional well-being of people needing support, and also a duty to provide comprehensive information and advice about services in their local area – even for people who are not eligible for publicly funded support. The Act also introduces a legal entitlement to Personal Budgets.

The Act will create new opportunities for ULOs, particularly in the area of providing accessible advice, signposting and personalised support for people using Personal Budgets. Many local councils will be contracting this work out and ULOs have just the kind of knowledge and skills they will be looking for to help people make good decisions about care and support and to make sure that they have choice and control.

There are also some slightly more specialist areas offering opportunities for ULOs. For example, the Act requires that people have access to independent financial advice about care and support so that they can get support to plan and prepare for the future costs of care.

The Act is also intended to encourage a move towards more outcome and needs based assessment and councils will also have funds to contract out assessment work so ULOs with suitably qualified staff could be well placed to pick up some of this work.

Finally, there are various parts of the Act that require people to have access to independent advocacy. This is an area that several ULOs already have experience so this will obviously create further opportunities.

The Care Act in Practice (conference) is a crucial professional development event for senior social workers and social care leaders. In spring 2014 the care bill made its final passage through Parliament and gained Royal Assent. The conference will provide practitioners with an essential guide to the new legislation. See https://careact.govtoday.co.uk/overview
A Welsh user-led organisation is aiming to become the first in the UK to set up a co-operative that will allow disabled people to pool their support funding and secure greater independence and control over their lives. Disability Wales has won a Big Lottery Innovation Grant of more than £500,000 to set up Citizen Directed Co-operatives Cymru (CDCC), in partnership with the Wales Co-operative Centre. CDCC will offer an alternative to existing local services that support disabled people who receive direct payments - cash payments provided instead of local care and support services, which allow recipients to employ their own personal assistants (PA). CDCC will be able to pool all of its members' direct payments and so "maximise their effectiveness", allowing CDCC to employ any PAs needed by those members, and providing service-users with greater flexibility and control. The project will complement the Welsh government-funded Enabling Wales programme, which is creating two new centres for independent living and developing new, young disabled leaders in Wales.

The two projects will contribute to the Welsh government's Framework for Action on Independent Living, which was set up as a result of Disability Wales' Independent Living Now! campaign. Derek Walker, chief executive of the Wales Co-operative Centre, said: "The new project will demonstrate that co-operatives can used by groups of individuals to collectively commission, manage and control their own support that precisely meets their needs. "This new approach will not just be citizen-directed, but citizen-owned and citizen-controlled as well."

Professor Mark Drakeford, the Welsh Labour health minister, said: "It is through such collaboration and delivering practical leadership and action that we will achieve our vision of a greater voice and control for citizens and their right to live independently in the community. "This will complement our wider promotion of co-operative and social enterprise models for health and social care and help us in our aim of transforming social services."

18 June 2014
Disability News Service
What is NHS Citizen?

NHS Citizen is a project that aims to answer a simple question: what is the best way for NHS England take into account the views of all the public when it makes decisions?

NHS England wants you to be actively involved at its very heart. To help solve long-term problems, deal with ongoing issues, and take part in its decision-making.

NHS Citizen’s Assembly and the NHS England AGM in London on the Thursday 18th September 2014. The event will take place at the Queen Elizabeth Conference Centre, Westminster, Broad Sanctuary, Westminster, London, SW1P 3EE.

NHS Citizen allows members of the public to put forward their thoughts, concerns and vision for the future of the NHS. These ideas will then be discussed at the NHS Citizen Assembly Meeting, where Members of the Board of NHS England, NHS senior managers and members of the public will work together to shape the future of the NHS.

The day will contain lots of opportunities for patients, carers and members of the public to debate, deliberate and work together to explore solutions to issues important to health and well-being in England.

Further information on how to register for a place is here http://www.events.england.nhs.uk/all/153

If you require support to attend the event please contact Mary Newsome: mary.newsome@nhs.net – 0113 825 1338 and we will discuss how we can help you. Please note that NHS England will only pay travel, expenses and accommodation for patients, carers and volunteers to attend the NHS Citizen Assembly, the NHS England Assembly which follows on from this is a public event and will not be covered by our expenses policy.

Registration closes: 14th September 2014
National Voices has launched some new web pages which offer a really easy digest of the best international evidence on ways to enhance person centred care. Person-centred care involves placing people at the forefront of their health and care. It ensures people retain control, helps them make informed decisions and supports a partnership between individuals, families and services. Evidence for Person Centred Care (http://www.nationalvoices.org.uk/evidence) explains to commissioners and others the results of 779 systematic research reviews worldwide. It covers the topics of: self-management; shared decisions; prevention; information support and improving patient experience. For each topic there is a downloadable ‘simple guide’ that explains the research and looks at patient focused interventions in relation to their impact on people’s knowledge; people’s experience of services; health outcomes and behaviours; and use of healthcare resources.

Call to Action on Domestic Abuse and Homeless Services

FaithAction are running a series of ‘Call to Action’ opportunities for faith based organisations to get in touch and inform our report on how faith works in Domestic Abuse and Homeless services.

We are after case studies, examples and information about current services – whether that being their sole piece of work or whether they just support a small number of those affected by the above issues. We will also be holding round table discussions in Birmingham and London – further information and how to book can be found on our website: www.faithaction.net

For further information, please call: 0845 094 6350
In 2011, a group of people from the disability sector in Christchurch, New Zealand, reviewed the options available to disabled people for their daily lives. They concluded that changes to the entire disability support system were needed to address long standing concerns about how the government supported disabled people. Their report was entitled ‘Enabling Good Lives’. Half the members of The Enabling Good Lives Leadership Group are disabled people, and include disability sector leaders and Māori and Pacific members. Christchurch’s earthquake was the third most expensive insured natural catastrophe in history. This opportunity to relook at the approach to the support of disabled people called for a more person centred approach to well-being and health care and more joined up thinking between agencies working on supporting people.

Enabling Good Lives - Five Elements for System Change. The five elements are:

1) Building knowledge and skills of disabled people: to ensure disabled people understand the direction for change, and can take up opportunities to have more choice and control over their supports

2) Investment in families: to assist families/whānau to best support their disabled family member to have a “good life” and help them develop a vision and aspirations for what can be achieved

3) Changes in communities: to ensure communities, including businesses, workplaces, schools, and religious, cultural, sporting and recreational activities, are accessible and welcoming. Communities also need to recognise the contribution that disabled people can make to enhance cohesion and well-being

4) Changes to service provision: to align organisational roles and functions, delivery models, workforce capability, accountability measures, monitoring and evaluation with the vision and principles of the transformed system

5) Changes to government systems and processes: to support the system redesign e.g., integrated contracting, individualised funding, flexible outcomes-focused contracting, funding pooled from across Votes (may include Vote structure changes) and involving disabled people and families in governance.

Two people from this project Gordon Boxall and Gary Williams presented a talk at the LSE on how these changes were being implemented and their personal
experiences of the impact of this new approach. Together they presented a very personal story of being involved in an exciting new approach to support. This new approach is very much like the person centred support being promoted here in the UK but with a broad range of services involved. Out with the old and in with the new

OLD WAY - Someone else makes decisions about what support you get and when you get it

NEW WAY - With support, you decide what’s important to you to have a good life
As Enabling Good Lives expands over three years, increasing numbers of disabled people will be able to be part of it. By its third year it is expected that at least 300 people will be included in the project.

For more information click on Enabling Good Lives
For more information click on Enabling Good Lives

The NHS Constitution establishes the principles and values of the NHS in England.

EASY READ

• The NHS belongs to us all
• It cares for us when we need it most.
• This booklet talks about:
  I. the things that are important to provide good NHS services to patients
  II. Your Rights as a patient, what you can expect from the NHS if you are a patient

There is an easy read version available on line click here opens as a PDF Click here for a text only easy read version
Song for a Recalcitrant Bus Driver

She’s got places to go, she’s got things to do
(The train leaves for Brighton at quarter past two)
Not wait on the pavement admiring the view.
That’s why the lady needs the ramp.

She’s doing the things she chooses to do.
She’s going to the Tate and the Whitechapel too.
She doesn’t take any nonsense from you.
That’s why the lady needs the ramp.

She’s taken trouble dressing up fine,
She’s planning to taste the fruits of the vine
And conversation more exciting than mine.
That’s why the lady needs the ramp.

We fought for these spaces in midsummer heat,
Blocked all the traffic on New Oxford Street.
There weren’t any pushchairs patrolling that beat.
That’s why the lady needs the ramp.

She’s socialising, out and about.
She’s getting on here, you be in no doubt.
So tell all those pushchairs they’d better move out
Because the lady needs the ramp!

Allan Sutherland
Over the last decade or so surfing has taken on new and exciting challenges in the lives for not just abled bodied people but for people with disabilities and other access requirements. Surfers have discovered the huge benefits of the sport working with people with autism and for people recovering with post-traumatic stress disorder. Here are just two projects based in Cornwall.

**The Wave Project** began in 2010, when the local NHS Trust in Cornwall funded it to run a six week pilot scheme to examine the benefits of surfing on the emotional health of young people working with professional services. The results of the pilot showed that going surfing once a week helped clients feel more confident, improved their outlook and gave them a sense of fun. Since then, The Wave Project has developed an award winning intervention that uses the local surfers to help young people reduce anxiety and improve their emotional health. New projects have been set up all over the UK, including in Wales, Scotland and even inner-city London!

**Surf Action** is a charity dedicated to supporting military veterans (including TA and reservists) and their families, especially those affected by PTSD and physical injuries or struggling to re-adjust to civilian life. People often describe emotions as coming in waves. That’s why surfing works!
Ann Nutt who is a member of Shaping Our Lives (SOL) management board recently went to Melbourne to attend the joint world conference on social work. She gave a report back on her experience.

Was it worth it?
Yes, there were many issues Peter Beresford and I challenged before I left the UK:

- The current bursaries do not support applications from service users
  - This is now being reviewed
- We have now secured that service users can have reduced rates (same as for students) for booking fees to attend conferences
- The organisation which was managing the conference are now aware that Carers/Personal Assistants supporting service users do not pay the booking fees
  This will benefit service users and carers that wish to attend conferences in the future.

My presentation was well received and all my hand-outs that included links to leading UK organisations disappeared very quickly. My presentation was on the subject of user involvement in social work education past, present and future.

I had also submitted a similar abstract to the Global Observatory and this was referred to by the International Social Work bodies during my stay. The content of my abstract attracted many representatives and I was interviewed by the Guardian and Prof Peter Beresford followed this up with a supporting article.

The conference is still an Academic led event with little input
from practitioners, service users, carers and students this was evident in the closure thank you which raises the question whether there were any user involvement in this year’s conference.

Many of the International Organisations on Social Work Education were at pains to tell me that service users will be involved in the next "Social Work Day" in March 2015 (see page 13) and there will be a conference in Edinburgh later this year and service users are currently being involved in the planning of the event. PowerUs (This is the Leonardo project I have been involved with for the last 2.5 years) SOL is a major partner and we will be involved with the planning of the Milan conference next year.

This led me to add an extra piece to my presentation on meaningful engagement and what it means. To my surprise many people came up and said they do engage with user groups but really only to have their decisions ratified. I admired their honesty

One of the main issues being discussed was the ageing population and dementia also the role of their carers this is a global issue and not just a UK problem. I found some of the research work currently being carried out in Japan fascinating and I am delighted that a Professor from one of the Japanese universities wishes to meet members of SOL in her visit to the UK later this year.

One piece of research on older people gave a larger role to the hospital pharmacy team and I have agreed to give feedback to the Chief Pharmacist at my local hospital on this item.

There were many advantages to attending the World Social Work Conference in Melbourne

- It raised the profile of service user engagement
- The benefits of engaging with user led organisations
- An opportunity to show case good practice
- Network with our European/worldwide colleagues

My thanks must go to the following user led organisations and local organisations for the financial support that enabled me to attend.

- Shaping our Lives (SoL)
- Social Work Education in Practice (SWEP)
- ECDP (Essex Coalition of Disabled People)
- Essex Participation Advisory Group (E-PAG)
- Harlow Social Club for the Physically Disabled,
- Harlow Health Centres Trust and individual donations
Out of the Box workshops underway!

Out of the Box creative participants have now started taking archives out of the box!
The first group spent Friday (4th July) afternoon exploring Tower Hamlets Local History Library and Archives and going through a variety of materials whilst sharing their own personal stories on the East End. Click here to view photos of the day!
Their research and ideas will continue in the following two workshops, led by digital and video artist Caglar Kimyoncu, with their creative responses taking shape and form.
Another exciting journey has begun and we are all eager to see where it takes us!
Following these collaborative workshops, participants’ responses will be incorporated into the Out of the Box exhibition, to be launched at the Tower Hamlets Local History Library and Archives in November 2014, as part of Disability History Month. A series of public events and talks will complement the exhibition, which will then tour across the Idea Stores and libraries in Tower Hamlets during 2015.
The team is looking forward to meeting the other two groups in the next weeks!
In the meantime, you can follow the project online on facebook and twitter (#outoftheboxproject).
Out of the Box is a creative partnership between Tower Hamlets Council’s Local History Library and Archives (www.ideastore.co.uk) and filmpro ltd (www.filmpro.net), funded by the Arts Council England (www.artscouncil.org.uk) and supported by The National Archives - Archiving the Arts (www.nationalarchives.gov.uk) and One Tower Hamlets (www.towerhamlets.gov.uk).
Find out more via www.outoftheboxproject.org or contact us on info@outoftheboxproject.org / 020 7613 5856 / 079 4451 359)
Since August 2012, Disability Arts Online has been publishing writing by members of the Grace Eyre Foundation creative writing group. The Grace Eyre Foundation offers a range of inclusive day activities to over 100 people with learning disabilities in Brighton & Hove. DAO aims to enable individuals at the Grace Eyre Foundation to build an online profile of writing about their activities, interests and aspirations by publishing a showcase of galleries of artwork, creative writing and a blog.

An Earthworm called Girlfriend and Other Stories’ by the Grace Eyre creative writing group

My Dad by Johnny Schachter

I love my dad
He was the best pal I had
But he could be scary.

When dad got sore
He would have bulging eyes
And what is more
To my surprise
He would roll up his tongue.

My father was extreme
He could be cruel but compassionate
He could be mad at it
Like a subject or a person
But he was a human.

Sometimes he would scream
Or be in an explosive rage
The gentle bear would turn into a lion
Once he threw a glass flying
But I have learned in my old age

We all have our faults
And we live in a world of imperfection
With dad, one could be delighted
But his fuse could be ignited.
Under the Westway in West London there is a very special yoga class for people with mobility disabilities which offers everyone the practice of classical yoga. The class is taught by Frederique Sardais, a very experienced teacher, who trained in adaptive yoga in the US with the founder of the technique. Currently this is the only adaptive yoga class in the UK being given by a specially trained teacher.

The loyal and enthusiastic regulars include wheelchair users with cerebral palsy and spinal cord injuries, plus people with a wide spectrum of ambulatory disabilities from cerebral palsy, stroke, or amputation. Under the thorough and encouraging tuition of Fredee (as the teacher is known) yoga poses are adapted to individual needs with help from props and assistants. The class always begins with Fredee asking everyone how their body and mind are feeling and making sure everyone has the blocks, belts and extra mats they’ll need. Then the room quietens and Fredee guides everyone, including assistants and carers, to become mindfully present at the class and to set their own silent aim for their yoga practice, in her words ‘prepare your mind to do yoga’.

When the class gets to dog pose the assistants help wheelchair users to transition to a mat, or to stand using a chair or the wall for support, while Fredee goes round the group, gently repositioning and providing grounding with manual touch to make sure everyone achieves the challenges and stretch of the pose in their own way. Regular attendees may give assistance to each other, and the class has developed a uniquely co-operative practice of yoga. For example a wheelchair user will hold the feet of someone lying on their back on a mat, to provide traction and support; in turn the person who can stand may support the arm of a wheelchair user so they experience a version of Trikonasana or Triangle pose. By this time no one is on the mat they started with, the chairs and props are all round the room and the atmosphere is joyful chaos. Participants have reported that practising yoga has made them calmer, enabled them to relax and able to deal better with stress and pain, given them more muscle tone and improved their balance and posture.

www.yogawestlondon.co.uk or from September our new website at www.adaptiveyogauk.com
PowerUS: conference partner at social work conference in Italy

Following on from the success of the launch of www.powerus.se (a European funded project looking at service user involvement and social work education) the PowerUs group is now a partner for the conference "Social Work Education in Europe: towards 2025" which will be held in Milan, Italy, from 29th June to 2nd July 2015.

The event will discuss the major breakthroughs and developments in the field of Social Work education, with a specific focus on Europe but from a global perspective. In addition to a top-rate scientific and educational program, there will be many opportunities for networking, hands-on learning and sharing experiences and ideas about the future of social work education.


Mending The Gap with Young People in Durham

On July 22nd, (40) students, lecturers and social workers came together with (14) young people to mend the gap. The event was funded by The Higher Education Academy and it was developed with a group of young people from Investing In Children (children's rights organisation) in partnership with students at New College Durham.

The aim of the event was to identify gaps between young people and adults in social work (or other) roles and explore how gaps could be mended.

After lunch everyone went to their selected activity from the options of; football, dance, learning about a car engine and playing interactive computer games. Apart from being good fun this was an important feature of the gap mending approach which emphasises the importance of people meeting as people first.

The information from the day will be written up and shared within PowerUs and further developments are underway.

Young people had identified the gap between themselves and politicians in the planning stages of the event and invited a local Labour MP (Roberta Blackman Woods) a meeting was arranged which took place last week with 8 young people and 6 social work students. Young people talked about their lack of involvement in decision making in a range of contexts. This was a useful discussion and a positive start to mending the gap with young people which we aim to develop further by running our second gap mending programme at New College in the next academic year.

To read more about mending the gap at New College Durham click here
A video dinner party with an alcohol-infused butler, a tender look at Alzheimer’s and family relationships, a frank and funny sex comedy, non-dancers dancing and an exploration of religion’s attitude to disability are all part of the extensive programme at Southbank Centre’s second Unlimited Festival.

Following the outstanding success of Southbank Centre’s first Unlimited Festival, one of the highlights of the Cultural Olympiad in September 2012, the much anticipated second festival will continue to celebrate the artistic vision and originality of disabled artists with an ambitious mix of theatre, dance, music, literature, comedy and visual arts. Works presented will include nine commissions from the Unlimited programme, an unprecedented £2.4million, three-year initiative funded by Arts Council England, Spirit of 2012 and Creative Scotland which funds disabled artists to produce work which aims to transform our perception of the world.

Unlimited Festival takes place throughout Southbank Centre, including Queen Elizabeth Hall, Purcell Room and spaces inside and outside Southbank Centre’s Royal Festival Hall. Southbank Centre’s Queen Elizabeth Hall is being transformed into a blackbox theatre with all members of the public using the entrance normally used only by disabled members of the audience.

Please click on this link to see the programme details on the Southbank Centre’s website

Please click on this link to visit the Unlimited website
Beyond the Usual Suspects
The focus of this report is making it possible for everyone who wants to, to be more involved in and have more say over their lives and the services they use to live them. This aspiration has come to be framed in terms of ‘user involvement’. The report draws on findings from a national research and development project supported by the Department of Health, which aimed to find out how this could be achieved.
Click here to see the electronic versions

Supporting people Towards a person-centred approach
There is widespread agreement that care and support services must change radically if they are to meet the rights and needs of the rapidly growing number of people who require them. For the first time, Supporting People explores with service users, practitioners, carers and managers what person-centred support means to them, what barriers stand in its way and how these can be overcome. A comprehensive book, Supporting people: Towards a person-centred approach is published for JRF by The Policy Press, price £19.99 rrp (plus £2.75 p&p).

Disability Studies : a student’s guide by Colin Cameron who is a member of Shaping Our Lives management board and senior lecturer in Disability Studies and Social Work at Northumbria University, Newcastle.
This textbook brings together a wide range of expert voices from the field of disability studies and the disabled people's movement to tackle the essential topics relevant to this area of study. From the outset disability is discussed from a social model perspective, demonstrating how future practice and discourse could break down barriers and lead to more equal relationships for disabled people in everyday life.
Reflective questions and suggestions for further reading throughout will help readers gain a critical appreciation of the subject and expand their knowledge.

More information can be found on our resource page click here
Shaping Our Lives National User Network is a national user controlled, independent organisation, ‘think tank’ and network that was started in 1996. It wants to see a society that is equal and fair where all people have the same opportunities, choices, rights and responsibilities, a society where people have choice and control over the way they live and the support services they use.

What are our aims?

- to support the development of local user involvement that aims to deliver better outcomes for service users
- to give a shared voice to user controlled organisations
- to facilitate service user involvement at a national level
- to work across all user groups in an equal and accessible manner
- to improve the quality of support people receive
- to enable groups to link to other user controlled organisations
- to develop links with worldwide international user controlled organisations

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