Vote, Vote, Vote For A Better Future!!

Hello Everyone. Hope you’ll find lots to interest you in this edition of the Newsletter – for which a big thank you to Eamon. Shaping Our Lives are having another busy year – one of the great joys of which is meeting service users from different parts of the country and finding out more about all the good things that you are doing. But of course the down-side of our work are the increasing problems you and we encounter because of the massive cuts that have been taking place in public services and support for disabled people, mental health service users, older people and others who need long term support from health and social care. This, together with the oppressive cuts being made in welfare benefits is making life increasingly hard for growing numbers of people, with disastrous effects for some. Continued……….
Continued from page 1........

I truly wonder how much longer things can go on like this. The Institute for Fiscal Studies recently said that the cuts that are being made in state services and expenditure are taking us back to the days of the poor law and we can’t know what long term effects this will have. That’s why I want to ask everyone who reads this newsletter to try and vote at the general election in May.

This is a key time for real user involvement, when we have it in our hands to decide what kind of government we want for the future. Politics are complicated and often nasty, but I hope people will feel able to use their right to vote to try and get the kind of services and policies that will be most helpful for service users for the future.

I’m certainly not going to do what most politicians do, which is to tell you who to vote for, but I do hope I can encourage you to make every effort to cast your vote. Here’s a real chance to make a difference for your future and all our futures.

Peter Beresford Co-Chair
Shaping Our Lives


NEW DATE & DETAILS!

University of the West of Scotland (Paisley Campus)
Friday 10 - Saturday 11 April 2015

In the context of savage cuts in public sector funding, ever increasing social work managerialism and stigmatisation of service users, this conference will provide an important opportunity to debate ways of developing networks of resistance necessary to defend social justice-based social work and oppose the politics of austerity.

Plenary sessions will include presentations on the following themes:
• Racism, antiracism and social work practice
• Radical practice today: voices from the frontline.
• Global perspectives: radical social work in the world today

More conference details & call for papers on flyer below.

Click on the following link to register online:
https://eventbrite.com/event/2004729199/
"VOICES is one of 12 projects helping people with multiple needs nationally. It is funded by the National Lottery through the Big Lottery Fund as part of Fulfilling Lives: Supporting people with multiple needs. VOICES is coordinating services to meet the need of some of the most vulnerable people in the community. Customers of the project have experienced combinations of homelessness, mental ill-health, addiction, and offending behaviour. VOICES is aiming to understand and learn from the lived experience of people with multiple needs. This is to support access to services, challenge stigma and stereotypes, and promote systems change. It is a partnership project including a wide range of voluntary and statutory sector organisations. At the heart of the VOICES partnership is the Expert Citizens. This is a group of people with lived experience that helped to design the project and are now supporting it as leaders. VOICES aims to support nearly 400 people over its 8-years towards their recovery and identify then implement more effective approaches to supporting people with multiple needs."

The Expert Citizens were formed just over two years ago, to originally support the fulfilling lives bid for Stoke on Trent, and were successful in doing so. The VOICES project received near to 10 Million Pounds to support people with multiple and complex needs within the City of Stoke on Trent. The Expert citizens are an independent organisation, we have our own constitution & mission statement. By sharing our lived experience we are able to influence organisations and support systems change. To date, we have consulted with other organisations that work with people with complex needs; these include the regional homeless forum, the successful bidders who took over the probation service and the department for work and pensions. We have also been commissioned by organisation LankellyChase to give our professional feedback in relation to the Hard Edges report, Research into severe and multiple disadvantage in England. Darren Murinas, Vice Chair of the Expert Citizens says …

"I recognise the lives described in this report. I’ve lived It myself. I was lucky……… Continued…….."
I got the help I needed to become clean, sober and responsible citizen after a childhood of neglect and a lifetime of crime. I am really glad that LankellyChase Foundation is focussed on this issue and continues to relentlessly ask questions about why more progress is not being made to help all who need it become engaged citizens of their communities. Change is possible. But only if the system recognises it needs radical change.”

“Every agency in Stoke on Trent will learn to listen to the voices of people with complex needs and to change their services so they are appropriate and accessible to them. Every person with complex needs will therefore be heard and offered new hope and support until they have journeyed to where they aspire to be. Seeing the results of these changes in our city, society at large will learn to empathise with people with complex needs.”

‘Expert Citizens Mission Statement’

Expert Citizens on Twitter: @ExpertCitizens
VOICES on Twitter: @voicesofstoke
VOICES website: www.voicesofstoke.org.uk
VOICES on Facebook: www.facebook.com/voicesofstoke
VOICES on YouTube: www.youtube.com/user/voicesofstoke

Big Lottery Fund: http://www.biglotteryfund.org.uk/
Fulfilling Lives: http://www.biglotteryfund.org.uk/prog_complex_needs
Disabled activists are hoping that a new campaigning coalition will make their county a focal point for highlighting the damage caused to disabled people by austerity-related cuts. Disability groups in Derbyshire decided to launch the coalition after hearing last year that Derbyshire county council was planning to make an extra £157 million in cuts in the five years from 2013-14 to 2017-18, reducing its spending by a third. Backing for the coalition has come from Derbyshire members of Disabled People Against Cuts (DPAC), the Chesterfield-based disabled people’s organisation Disability Campaigners, Learning Disability Carers Community, the Chesterfield self-advocacy organisation Our Vision Our Future, Learning Disability Alliance England, the union Unite’s community membership arm, and Mencap’s north of England region. Coalition organisers are hoping to sign up dozens more organisations. Among the measures already announced, Derbyshire council has increased care charges, and tightened eligibility criteria for council-funded care from “higher moderate” to “substantial”; and a new £5-a-day transport charge is set to be introduced in April, for disabled people travelling to day centres and other activities. Gary Matthews*, himself a DPAC member, said the cuts were sparked by huge reductions in the council’s government grant, but he pointed out that “the way that the council was initiating them was really targeting disabled people”. He said: “What we would like to do is make Derbyshire an example to the rest of the UK about what we can do and how we fight back.” The coalition – which has yet to be given a name – has launched a survey of disabled people and carers, as well as a petition, and has written an open letter to the council.

*To contact Gary Matthews, call 07710 430547 or email matthews354@btinternet.com.

5 February 2015

Original report from http://disabilitynewsservice.com/
Hi I am Sam and I am a CP Sufferer which I gained at 9wks old from a miss cot death. I exceeded my family's expectations and went to university and gained a degree. After 9 years and after redundancy I decided I did not want to work in an office environment again. I ended up getting a part time job at a local vets which I still do and love but it gave me time to think about what I really wanted to do. I went back to the idea of being a zumba instructor. When I was researching what I would need to work with disabled clients I came across Instructability. Instructability is a programme run jointly between Aspire and YMCAFit to train unemployed disabled adults to become gym instructors. After training I completed a 12 week work placement at a local gym. After that I finally did my Zumba B1 instructor training.

I love teaching it, its very adaptable and suits everyone. I love the fact that I am pushing my regulars with their fitness and helping their balance, co-ordination and weight loss goals.

My biggest achievement was winning an award for 'most outstanding support for adults with additional or special needs' and was runner up in 'most inspirational instructor – South' I have gone on to work with the local GP Referral Team and help clients get back in to fitness to help improve their health. I also have been working with Clubbercise to design a disability adapted version of their routines so that all their classes can be open to disabled clients. This will be the first to design a adapted version of its routines so that disabled clients do not have to go to separate classes. This is one of the biggest achievements so far.

If anyone would like to contact me please feel free via my website or my facebook page. I am happy to assist disabled people with their fitness goals, I am available to train instructors up on disabled clients and am available for fitness conventions or conferences to talk and do demonstrations on the subject.

Http://samjames.zumba.com
www.facebook.com/samjfitness
twitter id: samborambo
10 SVI (Sandwell Visually Impaired) members are scaling the heights and there’s no dampening their ambition to climb even higher! These intrepid would be mountaineers turned out in mid-August 014 for a 12 week course on wall climbing at the innovative health and leisure Portway Lifestyle Centre in Sandwell. Under the expert eye of 3 tutors from ‘Closer to the Edge’ who operate the adventure outdoor pursuits centre in Sandwell Valley, SVI members are learning to tie safety knots, adjust a safety harness and operate the safety line. They learn to climb up to 8 walls graded for a range 3 to 8a in difficulty and stretching between 6 and 10 metres high. The young whipper snappers (in their early twenties), Lee, Mark and Johnathan make it look easy but the ‘oldies’ (in their late 40s to mid-70s) aim to catch them up and all gained the first stage wall climbing certificate. Funded by a £1,000 grant from Sport Relief its magic for those who like to have their heads in the clouds.

Their prowess inspired the Sandwell Disability Activation Fund to meet the costs of this adventurous group progressing to level 2 and 3 of the National Indoor Climbing Award Scheme (NICAS). Spread over 12 weeks, climbing started in January this year with ‘Boulders Central at the training helm. Better still, those young whipper snappers, already into stage 3, are keen to act as Spiderman buddies to newcomers to climbing. It’s good to get away from the humdrum; the sky really is the limit for members of SVI!

Graham Price
Shaping Our Lives and Sandwell Visually Impaired (SVI)

http://www.bouldercentral.co.uk/
A new typeface is making life easier for people everywhere who live with dyslexia. Christian Boer, 33, is a Dutch graphic designer who created the font that makes reading easier for people, like himself, who have dyslexia, according to his website. Now, he’s offering it to people for free.

The typeface is called “Dyslexie,” and Boer first developed it as a final thesis project when he was a student at the Utrecht Art Academy in the Netherlands. The font makes reading easier for people with dyslexia by varying the letter shapes more, making it harder to confuse similarly shaped letters like “b” and “d,” for example.

Dyslexia is a language-based processing disorder resulting in a learning disability often characterized by difficulties with accurate word recognition, decoding and spelling, according to the National Center for Learning Disabilities. Research suggests that about 17 percent of the population has dyslexia, according to PBS.

Boer hopes the font will create more awareness around the problem of dyslexia, according to a press release. The font has been proven to get positive results, including a reduction in flipping and mirroring of letters and increased ease in reading for dyslexics. Independent studies at the University of Twente and Amsterdam found that nearly three-quarters of the students surveyed reported making fewer reading mistakes when taking a test written in the font, according to “Dyslexie’s” 2012 research. To download “Dyslexie,” or for more information, visit this site.
People's NHS - Our Mission Against NHS Privatisation
The Campaign
People’s NHS is a community run campaign to stop NHS privatisation. Across the country, thousands of people are fighting the sell off of their local services to profit making companies and the creation of a business out of our communities’ health.

Our mission is to pool all our resources, work as a unit, share what we know, and together, push against a government which is determined to undermine our healthcare by selling it to the highest bidder. And we already have some success stories to report.

We’ve stopped the George Eliot hospital from being sold off. And we pressured the government to provide emergency funding to keep East London surgeries open.
The NHS belongs to us all. It’s down to us to defend it. That's why we're the People's NHS.

Sign the petition, and help us spread the word.

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
Canerows – Wandsworth

Canerows is a service user-led group working to improve the experiences of people from Black, Asian and other minority ethnic (BAME) backgrounds in Wandsworth and operates under the umbrella of Sound Minds. Although Canerows has a BAME focus, peer supporters work with anyone who wants the service, regardless of background.

Founders Devon Marston and Coral Hines say that the core values underlying the service are that peer support can deliver what is frequently reported as missing in busy mental health settings, compassion love and ‘ordinary human kindness’.

The Canerows model has been highlighted as good practice in national reports by Mind, and Together and in commissioning guidance on creating effective services addressing the needs of BAME communities (Practical Commissioning Guidance 2014). Canerows has recently been awarded three years of funding from City Bridge Trust, enabling us to extend the service and organise peer support in secure settings locally.

A Ward Visiting Service - visits to local mental health wards. National reports regularly show that people in hospital complain that staff do not have time to talk to patients. Ward Visitors sit with, listen to, talk to and offer hope to people, from the perspective of someone who has been in that situation. Ward Visitors complete Canerows own training at Level 2 accredited by the Open College Network London Region.

A Post Discharge Community Support Service There is no expected skill base or menu of interventions for peer support workers meeting people when they leave hospital. Activities have included: playing tennis, going to a café, help to get voluntary work, accompanying someone to hospital appointments, help at home or with shopping and linking up with a drop in. Ward Visitors have the option of taking an additional accredited training, then take on community support role.
Regular training and consultation events
Canerows organises twice yearly consultation and social events which may include talks and discussions about local services, or training sessions. There is always food and music!

Mama Lows Kitchen – is a one day user led drop in operating from a nearby community centre, in partnership with Together and Wandsworth Council.

www.soundminds.co.uk
www.canerows.co.uk

Services – ring Sound Minds for details on 020 7207 1786

- Accredited Peer support training package can be combined with ongoing advice and supervision
- Entertainment for your event – from reggae band to jazz duo
- Film Services – short promotional films, documentaries, film classes
- A range of music, art and film related activities and tuition at our Battersea studio base

myageingparent.com has been set up by Alex Ingram and Deborah Stone:

“Both of us lost our fathers some years ago and have a single parent living. We know first-hand how important it is to try to ensure that our parents are happy, contented and as healthy as possible. So we developed the concept of myageingparent.com, a website aimed at helping you to help them, whether it is your elderly parent, older friend or relative. Packed full of information, it is a proactive site, which helps you find the answers to all the questions you might have. Whether you need specific information on care options, local authority funding, or how to keep them active, busy and healthy, myageingparent.com provides it all. And of course, there are many helpful articles on how you can cope with the stress of looking after your parents as they age.”

See more http://www.myageingparent.com/about-us/
Here are some links to our most popular titles

Index of titles

- Beyond the Usual Suspects

- User-driven commissioning: Building on the ‘lived experience’ of disabled people – the most under-used resource in social care

- Examples Of User Controlled Research

- The Standards We Expect

- Supporting people Towards a person-centred approach

- Developing User Involvement in Social Work Education

- Funding social care: what service users say

- Transforming Social Care: Changing the future together

- The Changing Roles and Tasks Of Social Work From Service Users’ Perspectives
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.


Public Health England action plan tackles health inequalities for men who have sex with men

The action plan, titled ‘Promoting the health and wellbeing of gay, bisexual and other men who have sex with men’, is the first of its kind from a national body. The action plan is being launched alongside a new programme of work which explores ‘The health and wellbeing of black and minority ethnic gay, bisexual and other men who have sex with men’ (BME MSM). The project aims to reinvigorate action and increase understanding of BME MSM identity, health and social care needs among professionals and the public.

Evidence shows that: just 7% of black gay and bisexual men have tested for any sexually transmitted infection compared to 26% of white gay and bisexual men: a third of Asian men and mixed ethnicity men have experienced domestic abuse since the age of 16 compared to 1 in 5 of white gay and bisexual men.

For a page of resources click here
One of the main aims for SPECTRUM’s User Led Organisation project is to build a strong and diverse network of ULOs across Hampshire. However, until recently, we have not been as successful as we would like in engaging some of the groups who are too often under-represented, particularly BAME and Faith groups and the Gypsy and Traveller community.

To try to address this we formulated an engagement strategy, which included identifying crosscutting issues that all groups are likely to have an interest in as a way of building bridges and encouraging participation. Hate Crime was identified as a strong candidate as it is an issue that effects many groups. The issue is also very topical and urgent as there is anecdotal evidence that Hate Crime is increasing as a result of community tensions created by welfare reforms, austerity and the debate about immigration etc. There is also known to be a long-standing problem with under-reporting of hate crime.

Consequently – with support from Hampshire County Council – we organised a workshop type event bringing together all the groups effected by Hate Crime as well as agencies who are in a position to help with addressing the issue – Police, Victim Support, Local Authorities, etc.

The event was held in October last year. More than 80 people participated from LGBT and Transgender, Gypsy and Traveller, BAME and Disability groups, as well as representatives from the Police, Crown Prosecution Service, Community Safety Partnership and other statutory organisations.

The day comprised of networking and workshops where groups shared their experiences and worked on recommendations and solutions to the problem of Hate Crime.

We are particularly pleased that the event successfully met the objective of extending our Network to groups with whom we have had difficulty engaging. Speakers included a Gypsy and Traveller group, a Transgender group and a speaker from the Muslim Community – all of whom have said that they would like to work with SPECTRUM again in the future.
We are currently talking to the Local Councils and other groups about what we can do to follow-up up the event and to raise awareness about Hate Crime. We have also produced a report from the event summarising the discussions and participant’s recommendations on action to tackle Hate Crime, which can be downloaded from the SPECTRUM web site. http://www.spectrumcil.co.uk/wp-content/uploads/Hate-Crime-event-Initial-summary-report-Dec14.doc

The right to speak up……..

Whistleblowing laws were brought in following tragedies such as the Herald of Free enterprise disaster. The legislation was intended to prevent workers raising concerns from being dismissed. This has failed abysmally as Sir Robert Francis stated in the Speaking up review, at best the law (Public Interest Discrimination Act) has limited effectiveness. http://freedomtospeakup.org.uk/the-report/

At least that gap is now acknowledged. It's been accepted. So whilst the law remains ineffectual workers remain unsafe. That's the least of our problems.

Patients First has grown organically from a handful of campaigners to a large and growing network of health professionals who have fought against a system that has been cruel and vindictive in too many cases. The stories of breakdown and loss have been heart breaking to hear. Personally I have listened to maybe thirty or forty similar heart wrenching stories of severe bullying, ignoring of the concerns and failing health and well being. Sir Robert Francis detailed similar in his report published last week.

Patients First contributed by submitting a summary of 70 cases in a thematic review. The patterns used to try and make the individual the focus rather than the issue are remarkable.

Attending a rally last week an eloquent doctor asked how listening to these stories Sir Robert could bear to leave these individuals unresolved. He has. There needs to be some process of reconciliation for the historic cases,
as well as most importantly learning from them. My own journey of whistleblowing took me through all the layers of internal management to the regulators and eventually the media. Until I received support from my MP and the media investigating the ~Peter Connelley story, I didn’t feel that my concerns were being listened to or taken seriously. Colleagues of mine who tried at the same time to speak up, resigned out of frustration, but also felt used by a system that didn’t really care to hear our views. NHS London who investigated my concerns in 2009, treated them as an employment matter rather than a patient safety issue, completely missing the point. The Health Select committee agreed that employment tribunals are not the place for patient safety matters to be heard. Yet this still goes on.

Now its clear that bullying is a major problem and can be linked to raising concerns. The leadership of the NHS will now have to start addressing that by training and more robust support for staff. Unions need to rethink their response to requests for help when staff report bullying, and much earlier intervention generally, and better psychological support is essential. I proposed an early intervention scheme which has been in principle accepted by NHS employers as a good way forward and currently sits with the Department of Health. This would allow an external scrutiny early one where clinicians or managers are raising concerns about patient safety. The focus would be the patient safety, not the individual.

Whistleblowing externally to regulators and politicians also needs to have a better system in place, and we need to see an end to the post code lottery that currently exists. Some people receive brilliant support from their MP, others have been ignored.

Campaigners have achieved a lot in having these issues heard and now accepted, now we look to government and politicians to ensure that there is fairness for all and no more turning away from difficult issues.

These are my own personal views.
I founded the Patients First network in 2011, contact them at patientspfirst@aol.com
@PatientsFIrst
Dr Kim Holt
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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