A word from our Chair

Welcome to this new edition of Shaping Our Lives’ newsletter. We hope you enjoy it and find it helpful. We have been working especially hard to keep in touch with you through electronic updates and on our networking website, SOLNET. Keeping in contact and sharing information is especially important in these difficult times, when many valuable public services are being cut, including health and social care support. Also many people are being badly affected by the cruel effects of the government’s welfare reforms. These are both stigmatising people badly and also cutting their incomes and increasing their levels of anxiety and uncertainty. We will continue to share the evidence about these changes and act as an independent voice for disabled people and other service users with determination.

Shaping Our Lives, of course, like other user led and disabled people’s organisations is also suffering as a result of these cuts and changes. Our long term security is put at risk and we are having to work all out to secure future funding, often in unequal competition with big and well funded charities and other organisations who are wary of being too outspoken on behalf of service users in case this damages their own interests.

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About Shaping Our Lives
Shaping Our Lives remains committed to supporting the involvement of all disabled people and service users and speaking out honestly and clearly on their behalf. To do this we have been discussing and developing our plans for the future and identifying possible partners who we can work with effectively and in an inclusive way. We have been doing important work for organisations like the Health and Care Professions Council, the National Skills Academy for Social Care and the College of Social Work as well as maintaining our role as a strategic partner of the Department of Health for user involvement.

We want to strengthen our national user group and also our management board. Please get in touch with us if you would be interested in being more actively involved in Shaping Our Lives. We hope you will be. You are the lifeblood of Shaping Our Lives.

**Everything we do we want to do involving you** – and we are really serious about this.

Peter Beresford

Email: information@shapingourlives.org.uk

or call Becki on 07956 424511

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**GET IN TOUCH WITH YOUR CLINICAL COMMISSIONING GROUP**

Increasingly, we are seeing evidence that health and wellbeing outcomes for service users are greatly improved when user-led organisations deliver services in their local communities. User-led organisations understand the needs of people with similar conditions better than anyone. They can deliver cost effective services, particularly meeting an increasing need for social prescribing alongside core medical services. Shaping Our Lives along with Disability Rights UK and CHANGE are targeting clinical commissioning groups (CCGs) to be more aware of using service user-led groups.

We are telling all CCGs and highlighting the efficiency both fiscal and in-service provision in commissioning user-led groups. If you belong or are a user-led group don’t be slow to approach your local CCG if you offer a service. You can find your local group by going to [www.england.nhs.uk/ccg-details/](http://www.england.nhs.uk/ccg-details/)

You could also join our network of service user groups to advertise your events and share information and knowledge. [www.solnetwork.org.uk](http://www.solnetwork.org.uk)

It is FREE for service user groups to join.
Welcome to Active Independence, one of the latest groups to join our networking website through our Twitter campaign.

**Active Independence**
We began in 2003 as a direct payment support group and organised quite a few events on personalisation and always offered our personal touch and knowledge. We promoted a personal centered approach to the service provision, due to our years of experience of using a Personal Budget for our care and support needs, we all employed PA/Carers so we followed our hearts. In 2011 we received some funding, became Active Independence, 100% User-led Organisation and then we became a charity.

We provide free advocacy, information & guidance, tips and training on a range of aspects to do with accessing and managing a care and support package including assessments, recruitment of PA/Carers and how to be a good employer, all focusing on the model of Person-centered care. The real strength of our group is that we are user-led, so any help to increase our voice and get involved with us by sharing your thoughts and experiences through our forums, by tweeting us, by following and commenting on our news stream, sign up for our newsletter or even join our committee and help shape the work we do is greatly appreciated. Our core belief is that Disabled people have the right to control the support they need in order to help them achieve independence.

Active Independence receives no money from or funding from our Council, but we help another council who appreciate what we do for their elderly and disabled. We received funds from them for our work, help and knowledge. We are well liked within the community, and once we have helped someone we receive thanks and acknowledgment from them personally or on our online testimonials. It is really nice and satisfying to know we have helped that person.

We receive funding and promotion from Skills for Care. We are in the process of doing our own PA Database through their last funding. We are true believers in what we do! We will continue to do it as long as we are able. We will fight the good fight to continue receiving funding.

Active Independence has a wealth of knowledge around disability issues which we have gained through years of consultative work, training and personal experience. And will continue sharing and helping others to achieve more.

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**Shaping Our Lives**
read online  [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)  newsletters
Independent Living Fund victory: Court win ‘is boost for movement’

A ruling by three appeal court judges that the government's decision to close the Independent Living Fund (ILF) was unlawful is a huge boost to the disabled people's movement, say activists.

Three court of appeal judges unanimously upheld the appeal, which challenged a ruling by the high court that the decision to close the fund in 2015 was legal.

The Department for Work and Pensions (DWP) will now have to rethink the closure decision.

The legal challenge was brought by five disabled people. The five claimants believe that closing ILF – a government-funded trust which helps about 18,000 disabled people with the highest support needs to live independently, by topping up their local authority-funded support – threatens their right to independent living.

The judges ruled that Esther McVey – at the time the Minister for Disabled People - had breached the Equality Act’s public sector equality duty when making the decision to close the fund in December 2012.

Stuart Bracking one of the claimants said: “It will hopefully give the disabled people’s movement confidence, and act as a catalyst for our organisations to work together to intensify the campaign and demand the closure of the fund is stopped,

He called for the large disability charities that had so far appeared ambivalent about saving ILF to now oppose closure and “demand a long-term future for the fund”. He added: “There is no fence for them to sit on anymore on this issue.”

Tracey Lazard, Chief Executive of Inclusion London, said she was "very proud of the supporting role" played by her organisation in the campaign to save ILF, as well as the support it had given ILF-users. Lazard said: "This is a real victory and the government should take note. This is disabled people fighting back and they need to genuinely consider our rights and the impact that their decisions are having."

She said she hoped the victory would be a "moment of reflection" for the big disability charities. "The charities have dismissed the ILF as dead in the water and we have shown that that is not the case."
Making health and social care information accessible

NHS England has begun a programme of work to develop and implement an Information Standard for accessible information.

An Information Standard is a framework of requirements and recommendations which health and social care organisations must follow, like a formal guidance document.

This guidance will tell organisations how they should ensure that disabled patients / service users and, where appropriate, carers, receive information in languages and formats that they can understand, and that they receive appropriate support to help them to communicate, which may include advocacy.

Getting involved

NHS England is committed to undertaking effective engagement at this early stage. This will ensure that their work is shaped by patients, carers, service users, clinicians and other health and care professionals, commissioners and providers of health and social care, and the public.

Engagement activity will be particularly targeted at understanding the views of people from the communities who are likely to be most affected. This will include people who are deaf or have some hearing loss, blind or have some visual loss, and/or people with a learning disability, as well as carers.

The views of individuals and groups working with people from these communities will also be particularly valuable.

They are also keen to understand the challenges people with sensory impairment(s) and / or learning disabilities face when trying to communicate with health and care organisations, and they want to learn from examples of good practice in this area from across the country.

They are currently planning engagement activities, including an online survey and face-to-face events, beginning in autumn 2013.

For specific queries in the first instance, including requests for information in alternative languages or formats, please email england.nhs.participation@nhs.net www.england.nhs.uk/ourwork/patients/accessibleinfo-2/
Living well with dementia

Dementia can affect the whole life of the person who has it, as well as their family. If you have been diagnosed with dementia, or you are caring for someone with the condition, remember that there is advice and support available to help you live well.

Even if you have suspected for a while that you or someone you love might have dementia, the diagnosis may come as a shock. People with dementia should try to remain as independent as possible and continue to enjoy their usual activities.

Over time, people with dementia will need help to cope at home and they may eventually need residential care in a nursing home. It is natural to feel worried about the future, but you are not alone – whether you have dementia or you care for someone with the condition. The NHS, social services and voluntary organisations can all provide advice and support to help you and your family.

Maintain a social life

It’s easy to feel isolated and alone if you or someone you care for has dementia. Keeping in contact with others is good for people with dementia because it helps them to keep active and stimulated. Some people find it difficult to talk about their own or a family member’s dementia, or want to help but don’t know how.

If a friend or a family member finds it hard to talk to you, don’t lose touch. Make the first move, explain that you still need to see them and tell them how they can help you. You may also find it helpful to join a local group of people with dementia and their families. You may not be someone who would normally join a group, but being part of a community of people with dementia or a group for families who have a member with dementia can be helpful. You are likely to be able to share experiences and gain insight and useful tips from others who are going through or have been through similar situations.

With thanks to http://www.nhs.uk/Conditions/dementia-guide/Pages/living-well-with-dementia.aspx

See the online version for the links to be active at www.shapingourlives.org.uk
Shaping our Age, supported by the Big Lottery Fund, was a joint project between the Centre for Citizen Participation at Brunel University, the Centre for Social Action at De Montfort University and older people’s charity the Royal Voluntary Service (formerly WRVS). The research challenged the common perceptions of ageing and sought to question the portrayal of older people and the assumptions that those providing services for them often make.

Shaping Our Lives was involved in interviewing a number of different groups including a black and minority ethnic group, lesbian, gay and transsexual group and residents of a residential home. Our interviews and findings contributed to a report. More information about this report can be found online at the www.royalvoluntaryservice.org.uk website.

Shaping our Age challenged negative perceptions of ageing by seeking to recognise the valuable economic, political, social and cultural contributions to UK society made by older people. It also sought to move older people from the margins to the centre of debates surrounding their well-being by supporting their active contributions to society.

In a period of austerity, it is especially important to re-evaluate traditional ways of working and to consider issues of sustainability and prevention. It is also timely to value the resources of older people and their potential contribution. We have found that a new generation of older people do not necessarily want to be associated with traditional models of service.

If ‘Darby and Joan’ clubs were a helpful traditional response to older people’s longstanding need for social connectedness, it is now time to take forward their twenty-first century equivalent and this is likely to be a participatory one. In this likely future scenario, the traditional ‘doing to’ model will have increasing limitations.

The involvement-led approach is not a panacea to address all the challenges of ageing. However, as part of a range of initiatives, we believe it can make a significant contribution to older people’s well-being and may have knock-on effects for other social care and health services.
DREAM
You carry your dream
Under your arm and walk about
When others knock about
And you may trip over
But don’t let it drop down
Carry it as if it is fragile
Most valuable agile, guile
Secret, sacred shrine
That in time will shine

Or in a plain or in a valley
Or on levelled play-ground
Or on the green and pleasant land,
Or in the dark deep ocean,
But it must be
In the heart of the heartland!

by Sasha Dee

Diagnosis: Hysteria? Prescription: Hysteria!

Poems by the Women of CoolTan Arts
CoolTan Books, price £5.99
Diagnosis Hysteria? Prescription: Hysteria! is an anthology of poems by the participants of the CoolTan Arts Women’s Poetry Group and some of the female staff and volunteers who work there.
Disability hate crime - new proposals on offences
by Katherine Quarmby

The Law Commission, an independent body set up by Parliament to recommend changes to laws, has just been looking at whether hate crime law should be updated. It has been consulting with disability groups, race groups, transgender groups and other equality groups to ask several questions about how hate crime laws could be improved.

The way hate crime is prosecuted and punished is not the same for all five groups. The Government has made tackling hate crime across all five groups a key priority, including how offenders are dealt with. The Law Commission asked two key questions.

The first was whether people accused of certain crimes, such as assault and criminal damage, should be charged with a specific aggravated form of the offence carrying a longer sentence if they had shown hostility towards the victim based on their disability (or other characteristic such as being gay, for example). At the moment, this only applies where victims have a particular religious origin or race.

The second question was whether there should be new offences of stirring up or inciting hatred against people with a disability (and other characteristics). At the moment those offences only exist on the grounds of race, religion and sexual orientation.

The Law Commission will consider the responses to its consultation over the winter and will publish its recommendations in the spring. I believe that we do need a specific offence of ‘disability hate crime’ in the same way that we have race and religious hate offences and I welcome the Law Commission’s proposals.

When I first started my investigations into disability hate crime back in 2007, there wasn't much evidence of incitement of disability hate crime, so I was less convinced then of the need for a specific offence. Now, I think there is more evidence of such incitement, because social media is so popular. It is easier for people to stir up hatred and therefore we need stronger laws preventing people from doing so, and punishing them if they persist in doing so. I’m hopeful that with specific offences on the statute book reporting will go up – and then we will get more convictions too.

Katharine Quarmby is a journalist, film-maker and author of: Why We Are Failing Disabled People. Portobello Books
Michael Doherty - Irish Travellers Movement in Britain (ITMB)

Amidst all the tantrums, sequins, lycra and make up, Channel 4’s ‘Thelma’s Gypsy Girls’, stumbled almost by chance upon the stark reality of what it means to be a young Gypsy or Traveller in 21st century Britain; the suicide of a Gypsy man.

The interruption of the reality TV show by what was only too real occurred when one of Thelma’s apprentices phones the office and says that she can’t make it to work because her cousin has just committed suicide by hanging.

What research exists paints a disturbing picture. A study of suicide amongst Irish Travellers in Ireland found that between 2000 and 2006, the rate of suicide among Irish Travellers was over three to five times higher than the total population. These figures are backed up by Thomas McCann, a psychologist who runs a Traveller counselling service. McCann says the incidence of poor mental health is increasing and the suicide rate amongst young Traveller women is also rising. He calls it “a crisis in the community.”

This epidemic of suicide is not confined to Irish Travellers in Ireland. The Traveller Movement say something similar is happening in the UK amongst Gypsy and Traveller populations. ‘Tell Someone’ was commissioned to raise awareness of this crisis.

Sybil Ah-Mane - Flexible Films

We had worked with ITMB on another film project before and so were very keen to work with them again. Travellers involved took part in shaping the content of the DVD chapters.

The films are split into individual stories and issues. There are also sections that speak directly to mental health workers – with examples of practices that have successfully adapted their service.

For more information about the DVD visit www.irishtraveller.org.uk

Tell Someone - a DVD for Travellers and mental health workers
Over 425 user-led organisations are already members of Shaping Our Lives networking website called SOLNET. It is free for service user led groups to join and puts you in touch with other groups and over 1,200 service users. SOLNET provides you with a space to give your organisation’s details, and if you wish, tell others about your work, advertise events, promote services and make announcements. After you join you receive a user name and password. You can request these again if you have mislaid them.

There are two areas available to members:

- The editors area where you can update your organisation’s details, about what your organisation does and who you work with and also add or update your contacts details.
- Members and friends area where you can add and edit items on the notice board as often as you want and update your personal contact details.

Members and friends are able to access other contacts listed which are not shown publicly.

Groups can post as many notices as they want and have access to a monthly e bulletin notice which reaches over 1200 different and diverse groups of people. This can make reaching out and seeking experiences and opinions from services users easier.

5 good reasons to join SOLNET:

1. Let us do the hard work and keep you informed of news and policy developments.
2. Be part of a national community of service users and user-led organisations.
3. Ask questions, share ideas, information and resources with similar groups.
4. Quickly find other organisations for partnership and service opportunities.
5. Help service users to find the support they need easily and quickly.

www.solnetwork.org.uk for organisations and user led groups JOIN NOW!

www.shapingourlives.org.uk newsletters
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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This newsletter is available in different formats on request.