The right to know…….

People using health and social care services are entitled to expect that their personal information will remain confidential. They must feel able to discuss sensitive matters with a consultant, doctor, nurse or social worker without fear that the information may be improperly disclosed. These services cannot work effectively without trust and trust depends on confidentiality.

But when does trust override access?

Recently a blind member of the board of Shaping Our Lives, caring for his partner who is living with Parkinsons with attendant dementia, tried to receive information in an accessible way from his partner’s consultant. Under the hospital guidance the consultant informed him that confidential information could not be sent via his preferred communication format because email was reckoned to be insecure. After lengthy, time consuming and emotionally exhausting attempts trying to resolve the issue, whilst having to care for his wife and not before the involvement of the health service ombudsman, was it eventually resolved.
This case was used in a report looking into the sharing of information within the NHS chaired by Dame Fiona Caldicott. In a quote from the report it says; Now citizens are a lot more concerned about what happens to their information; who has access to it, for what purposes is it used, and why isn’t it shared more frequently when common sense tells them that it should be. The review panel were astonished to learn from our Board member of the difficulty he had met in receiving information from the hospital that was accessible to him, saying in the case study embedded in the body of the report ‘so much for confidentiality when a third party is needed to access the information.

There is a need to listen to the experiences of service users and a need to strengthen the information networks that are proliferating with the wave of new technologies. Commissioners cannot organise the improvement of services unless they know quite a lot about the people using them. For example, they may want to build new care pathways that are better suited to people’s needs.

When it comes to sharing information, a culture of anxiety permeates the health and social care sector. Managers, who are fearful that their organisations may be fined for breaching data protection laws, are inclined to set unduly restrictive rules for information governance. Frontline professionals, who are fearful of breaking those rules, do not co-operate with each other as much as they would like by sharing information in the interests of patients and service users. There is a need to shift from being risk averse to risk aware in operating a sensible and fair policy of information governance.

A number of recommendations were put forward within the report:

- **You have the right** of access to your own personal records within the health and social care system.

- **You have the right** to privacy and confidentiality and to expect the health and social care system to keep your confidential information safe and secure.

- **You have the right** to be informed about how your information is used.
You have the right to request that your confidential data is not used beyond your own care and treatment and to have your objections considered, and where your wishes cannot be followed, to be told the reasons including the legal basis.

Across the health and social care system, most staff are required to undertake annual training in information governance. The commitment to training is important. However, the Review Panel discovered that the mandatory training is often a ‘tick-box exercise’. One nurse said the training was equivalent to an annual ‘sheep dip’, which staff could go through without thinking.

There needs to be a fundamental cultural shift in the approach to learning about information governance. Health and social care professionals should be educated and not simply trained in effective policies and processes for sharing of information.

Shaping Our Lives has long fought for the right for our voices to be heard and acknowledged. We are, as the maxim goes “experts by experience.”

Because of the board member of Shaping Our Lives' ability to articulate, to fight and defend his right to accessible information and with energy and fairness he was able to see wrongs righted. But not everyone can fight their corner as he has done in such a determined manner but it is important to be able to be heard meaningfully.

There is clearly an urgent and ongoing need for education and training in this area for staff, and also for patients and service users.

Shaping Our Lives would like to applaud our board member who despite huge obstacles was able to persevere and get information in an accessible way and in the process was able to highlight and to correct an inappropriate system as well as a communication malfunction to achieve a common sense result.
It is with great sadness that the Board of Shaping Our Lives learnt of the death of our colleague and friend Munir Lalani. Munir or Manny as he signed himself, was a longstanding and greatly valued member of the Management Board, Deputy Vice Chair and member of the National User Group. He was also actively involved in many other organisations and groups. He was chair of black health forum achi-Zindagi, a user-led charity working with BME adults from diverse backgrounds. We all feel the loss of Manny deeply, because he was such a positive human being, bright and witty, committed to equality and social justice. He represented all that is good and important about user-led organisations. We will all miss him greatly.
To see more tributes to Munir please go to the home page of www.shapingourlives.org.uk
Peter Beresford
Chair

Munir Lalani

Beyond the Usual Suspects

Involving service users has become a repeated mantra. For decades official reports, service reviews, plans for new developments have, as if by rote, included the phrase ‘services users must be involved.’ The few service users involved in this way have been exhausted. Critics have muttered about the reliance on ‘usual suspects’ and the risk of capture by the system. What has been more worrying has been the tendency to ascribe a simple homogenous view to service users, as if all service users are the same, share the same histories, and have identical views.
Arguing for an inclusive approach to engagement, these reports develop a compelling, thoughtful and genuinely inspirational approach. They challenge received wisdoms, while at the same time remaining absolutely focused on the need to involve the widest range of users at all levels of the decision making process.
All three reports are available to download from the resource library page of www.shapingourlives.org.uk for free or by donation for hard copies.
Contact information@shapingourlives.org.uk for more information.
PowerUs is a partnership between Lillehammer University College Norway, Lund University Sweden and Shaping Our Lives National User Network in the United Kingdom. It is funded by the EU Education and Culture Learning Programme. The aim of PowerUs is to develop and improve methods and opportunities for service user involvement in social work education, practice, policy and research.

PowerUs is developing a Charter for social work education that will provide a best practice model for service user and carer involvement. The aim of the Charter is that social work education is a partnership between people with lived experiences, practitioners, managers, academics and students. The principles of the Charter support inclusive involvement of service users and carers throughout the whole process including teaching, course management, planning, reviews, interviews, suitability panels, and placements.

Shaping Our Lives has been working with South Bank University who have piloted an involvement model learned from Sweden, of teaching service users alongside students for part of the social work course. The pilot is called ‘Advocacy, Partnership and Participation’. This is a social work teaching module where students, service users and carers learn together. Barriers are broken down and experiences are shared and can be taken into social work practice. At South Bank University they have found it improves capability of all those taking part. In particular, service users and carers said it would help in their day-to-day lives. Part of the module looks at user-led social enterprises and this has been critical for learning about and discussing user-led groups delivering advocacy services.

For more information please visit our website.

http://powerus.se/
A new idea: pooling your personal budgets together
by Luke Cardwell

Personal budgets paid for by social services have legally been available for disabled people to take control over their social services care package since 1996. Direct payments (money out of the personal budget to employ a personal assistant yourself or via a nominee) are now widely used across the country and many people find they help to promote a flexible and independent way for disabled people to live.

What is a more recent concept is those people who are in receipt of a personal budget or direct payments deciding to ‘buddy up’ together to pool those payments together and achieve a more flexible and affordable solution. Examples of how people can ‘pool’ their payments together include; collectively employment personal assistants, collectively purchase equipment, go on respite breaks or live together, split the costs for travelling, attend or run a social group or create your own social enterprise. It should be mentioned at this point that your local social services must approve any changes.

However, if you wish to pool your budgets together it is an exciting opportunity to identify common interests with other disabled people and merge your resources together to get the most out of what you want to do e.g. you and a group of disabled people could form your own social group and all pay so much out of your personal budget to club together a pot of money to pay for the venue, or the entertainment, or the travel costs (etc). You may live particularly close to another direct payment user and decide to pool your resources together to employ one personal assistant between you. So many different ways of using your direct payment/personal budget are available; it is not possible to provide an exhaustive list.

In Hull, East Yorkshire, I work as a Peer To Peer Support Development Manager looking specifically at facilitating these pooling arrangements. If you are residing in Hull and in receipt of a personal budget/direct payment please contact Luke Cardwell from Choices and Rights Disability Coalition on 01482 878778, or for those with hearing impairments, text-phone 01482 370986. Alternatively you can email Luke@choicesandrights.org.uk.

In addition, please feel free to make contact if you work for a charity/organisations involved with pooling personal budgets to discuss our project further.
Last month saw the sad news that Lucy Meadows, the Lancashire school teacher who recently transitioned from male to female, was found dead at her home. Many have spoken out in anger at Lucy’s representation in the media, especially in the Daily Mail, leading to a lack of privacy and harassment at a very difficult and sensitive time in her life. It’s crucial that people like Lucy have the support they need and that the media have a responsibility for realistic, sensitive and accurate reporting. Homophobia, transphobia is an irrational hatred and it thrives on diversity. It can show itself in countless ways, but in its most destructive form, homophobia can bruise, beat and even kill LGB people. Homophobic abuse is more common than most people think. If you have been shouted at in the street and called derogatory names or if you have been beaten or robbed or had your property vandalised because of your sexual orientation, it could be classed as either a homophobic hate crime or homophobic hate incident. But what is the difference? 

**Hate Crime**- any incident, which constitutes a criminal offence, perceived by the victim or any other person, as being motivated by prejudice or hate. 

**Hate Incident**- any incident, which may or may not constitute a criminal offence, perceived by the victim or any other person, as being motivated by prejudice or hate. 

**How to report & what to report?**
You may think that someone calling you names is no big deal, you may be used to it and have experienced it many times before but it is vital that you report any incident of homophobia. If you do nothing, no one will know what has happened to you and nothing can be done about it. It also means that other people may receive the same or worse abuse. 

If you or someone else is in danger then do not hesitate to call 999.

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*Say Enough is Enough!*
Why Report Homophobic Hate?
• Regular homophobic abuse - report each incident as it occurs and make sure that the police link your latest report with all previous reports. Have documents relating to the previous incidents to hand when you call, so that crime numbers and investigating officers’ details can be quoted.
• If you are unhappy - raise your concerns with a senior officer or a complaints officer.

This feeds into their intelligence systems, so every day when police officers and Police Community Support Officers are briefed about what is happening in their local area and what they should be on the lookout for, certain issues can be flagged up and responded to.
With thanks to the Lesbian and Gay Foundation.
www.lgf.org.uk

Diagnosis Hysteria? Prescription: Hysteria! is an anthology of poems by the participants of the CoolTan Arts Women’s Poetry. These poems are not only about mental distress, but about love and loss, the power of the natural world, being a woman, everyday joys and woes, the beauty of language Out now! order your copy by contacting sara@cooltanarts.org.uk or phone 020 77012696

A SPOONFUL OF MEDICINE
Depression, a tablet they give to you
Post a letter though the door
Trauma, an incident that just happens

.......... Stress:
living every day
Disorder a label given to people
Personality:
Behaviour learned
Disorder a label stuck on you
Auditory illusions, a conversation one has with one's self ...............waves on a different frequency
Telepathy does exist
Illusions, aspirations, delusions, misconceptions
here comes the 6th dimension
You tread on egg shells
You walk on glass
You are not here
Your blood is leaking out across the broken glass but you can not see and you do not feel
By the medication you were wounded
By the sword you are killed
Michelle Baharier
On 30th January 2013 SCIL changed its name from the Southampton Centre for Independent Living to SPECTRUM Centre for Independent Living

SPECTRUM is a User Led Organisation, run and controlled by Disabled People. Our guiding principle is that disability issues are human rights issue. We work to a Social Model of Disability philosophy. Our principle roles are to champion a world which celebrates and includes Disabled People and to provide progressive 'user led' services which promote and enable Independent Living for all Disabled People. We are non-impairment specific, supporting all Disabled People, irrespective of their impairments. Formed in 1984, SCIL has become increasingly important and influential in supporting, informing and assisting Disabled People to live independently. SCIL has cemented its reputation locally, regionally and nationally as one of the most respected, influential and innovatively progressive User Led Organisations in the UK. We regularly advise ministers, senior politicians and officers in Government on a range of progressive social policy initiatives. Throughout our history we have succeeded where others have not by maintaining clear aims, values and principles; by being pragmatic, progressive and innovative; and by leading from the front on issues we feel strongly about. Our immensely loyal team continue to work tirelessly and passionately for progressive social policy solutions to the barriers Disabled People face in their quest to live independently.

www.spectrumcil.co.uk

Shaping Our Lives new Resource Page
www.shapingourlives.org.uk

- Download for free over 30 documents including publications, reports and research materials all developed by service users.
- A place for you to share and exchange knowledge, working towards a more meaningful inclusive user involvement.
- If you have a resource that you wish to share please e mail information@shapingourlives.org.uk
Members of Manchester-based Human Rights organisation RAPAR have been working with the UK Disabled People's Council on an arts project which was unveiled in Bristol in 2012. The project has produced the country's only public art work created by the UK's “hidden community” of disabled asylum seekers. The mural is being installed in the “Bear Pit”, the multi-road roundabout in the centre of Bristol, and is composed of drawings and ideas from disabled refugees who have worked with artist Andrew Bolton. Manjeet Kaur lives in Whalley Range, Manchester, and is one of the RAPAR members who has worked on the mural along with RAPAR members Mary Adenugba and Sandy Broadhurst. Manjeet, who uses a wheelchair, is seeking asylum in the UK after her husband, a journalist and human rights activist, disappeared. She said: “Working on the mural and meeting other disabled asylum seekers from different parts of the UK has been a great experience for me. I feel much less isolated knowing that I am part of a wider community. Andrew, the artist, and Rebecca from the UK Disabled People's Council worked with us and helped us to articulate and illustrate all our anxieties, hopes and fears. I think that, for all of us, expressing these thoughts through the mural has been very educational and therapeutic.” One asylum seeker who has mental health problems and has no money and no fixed abode drew a picture of a sun hidden by a cloud, explaining: “For me, there is no sun.” Another refugee drew a picture of herself jumping out of a tower block when she sees a police car: “If the police come to my house, I will kill myself. I won't stop to ask what they want. I would rather die than be deported.”

The art work forms part of a national research project run by the UK Disabled People's Council with funding from the Big Lottery.

www.disabilitymurals.org.uk
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.
About Shaping Our Lives

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

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This newsletter is available in different formats on request.