Join the new Shaping Our Lives Networking Website

This is a new and exciting website run by and for service users. It is designed particularly for service user controlled organisations but individual service users and non user controlled organisations will also find it helpful.

Do you want to know what support groups are in your area?
Do you want to find out what events are taking place?
Could you help others by sharing your experiences and knowledge?

As a member your group can offer services, share information, ask for advice, promote events, swap experiences, network with other service user groups and much much more! Each group will decide what they want other people and organisations to see.

The more organisations who sign up, the better it will be! Our project worker, Eamon Andrews, will be getting in touch with you shortly to explain more. Or you can go to www.solnetwork.org.uk.

! SIGN UP NOW !
www.solnetwork.org.uk

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Hi! I am very happy to be back with Shaping Our Lives. I will be working on our new database network. This is a long awaited and much needed project for service users.

Service user groups will be able to give out information about what they are up to. They can tell others where they meet, and share experiences and good practise.

At the moment only user controlled groups can join the database, but if they want they can make their details available for others to view. I will be contacting a lot of people over the coming months to explain the network and to help any groups who want to join the network. Joining is very simple and the website makes it very easy and straightforward. If you would like to know more and/or join up visit the site at:

www.solnetwork.org.uk

Or you can contact me directly:
Eamon J Andrews
Networking Database Co-ordinator
Email: eamon@shapingourlives.org.uk
Direct line: 0845 241 2128
(Thursdays and Fridays)

Would you like to be more involved with Shaping Our Lives?

Shaping Our Lives National User Group is made up of service users who are interested in our work and who tell the Management Group, from their own perspectives, what they think of what we are doing and what we hope to do. It is important to Shaping Our Lives that the National User Group connects widely to local organisations, networks and groupings.

We currently have fifteen members on our National User Group and we are hoping to find three more.

The group meets three to four times a year in Birmingham. A fee and expenses are paid. If you would like to apply to become a member of this important group please contact Jenny Willis for more information. You can contact Jenny at the Shaping Our Lives Office:
BM Box 4845
London
WC1N 3XX
Tel: 0845 241 0383
Email: jenny@shapingourlives.org.uk
S haping Our Lives’ project on developing diversity in user involvement continues. This issue of the newsletter includes a questionnaire for service users that asks about your experiences of user involvement and your views on the barriers that can make it difficult for some people to get involved.

If you would rather be interviewed by telephone, please call the Shaping Our Lives office and we will arrange for someone to call you back. If you would like a copy of the questionnaire e-mailed to you, please send a message to: michael@shapingourlives.org.uk

Please also pass the questionnaire to any other service users or disabled people you think might be interested, or we can send them a questionnaire if you let us have their details.

The four local groups working on the project are making good progress with their plans. They have already had meetings that have looked at how to increase diversity in user involvement. They are now organising events and activities that will develop good practice for attracting new people to involvement. Three of the groups will be holding events that aim to attract service users who have not previously been involved in their work.

There will be an event in Bristol for women who have or have had problems with alcohol on 17 June. Black mental health service users/survivors are meeting in West London on 14 September; and a meeting for users in Manchester will be held in the autumn.

Anyone interested in attending any of these events, or finding out more about the project, can e-mail Michael Turner: michael@shapingourlives.org.uk

The next phase of the project will be the development of training materials which the local groups will test before a training pack is produced.

PRIZES!
There will be a detachable entry form on each questionnaire which you can fill in and return with your questionnaire in order to enter our prize draw. One £50 and three £10 High Street Vouchers will be awarded on 31st July 2006.
A National Voice is an organisation run for and by young people who are or have been in care. In this article Ruth Hayman, who worked on the organisation’s Management Committee for two years, explains the history and work of A National Voice.

This organisation founded its roots after the Government commissioned First Key to produce a feasibility study on consultation and participation of looked after young people. The organisation is run for and by young people who have been in care and aims to bring about change for the lives of young people currently being looked after and leaving the care of their local authority. This is achieved by giving a voice to young people often through consultation via surveys, which can be completed online or the snail mail route via local social services departments. The results of these then allow A National Voice to inform and influence central and local government decisions about the care that the young people are receiving.

Education

A National Voice also uses the data collected as an educational tool to professionals and the general public to try and bring about positive stereotypes of young people looked after. Currently A National Voice is working on an education campaign called Please sir, can I have some more, which recently found that young people felt they were not receiving enough education, and the education that was being received was not of an adequate standard.
No bin bag campaign

The organisation has also launched a No bin bag campaign to local authorities after consultation with young people, which found that too many of them were having to move their belongings around in bin bags and not given suitable or appropriate luggage. Many Directors of Social Services have taken this message on board after much campaigning, including bin bag fashion shows held at the Tate in London. In these areas young people are now provided with a suitcase when they move.

A National Voice also helps young people from all over England to set up and join in local in-care/aftercare groups and aids these people to change the care system for the better. Young people are helped to speak up and have an effect on decisions about the care system and are encouraged to send out good messages about themselves and tackle any bad ones.

A National Voice believes that the local and central government are corporate parents and they need to be informed of suitable changes to improve their parenting skills, in line with good practice. The organisation’s management committee consists of young people who are care experienced and they take on the role of running the organisation and being the decision makers. The management committee decides on the next campaign focus, always with a view to improving the care system and does not take their individual roles lightly. The young people sitting on the board are focused and passionate for positive changes and will always try and find a way around potential problems or setbacks.

A National Voice has been very grateful to the Prince’s Trust for hosting the organisation and for their guidance in moving A National Voice forward and will not allow themselves to lose momentum as this will mean losing momentum for all the young people currently in the care system and all those who will become part of this local and national corporate system.
Leeds Involvement Project (or LIP) was set up in 1990 as a project within the local Council for Voluntary Service. It was grant funded by Social Services and Health as a way of consulting people who use what were then called ‘community care services’. Lucy Wilkinson, the project’s Manager, reports on how things have developed since then.

In 1995, Leeds Involvement Project became an independent user-controlled organisation run by people who use adult social services - mainly disabled people including people with learning difficulties and mental health service users, older people and unpaid carers. We have developed over the years, retaining our core funding and attracting other sources of income, both commissioned work from service providers such as Primary Care Trusts and independent funding from, for example, the Big Lottery Fund and Comic Relief.

All our work is within our core aim of enabling people who use Community Care services to take control over their own health and social care needs through enabling the involvement of service users and carers in the commissioning, planning and development of health and community services in Leeds. We also have a strong value base and operate within 5 key principles:

◆ Promoting the social model of disability - that is people are disabled by barriers in society, rather than differences in their bodies or minds (a whole article in itself, I cannot do justice to this here but I am sure many Shaping Our Lives readers are familiar with this model) This means that we are increasingly working to improve "mainstream" services, as well as social care services

◆ Promoting a holistic approach to health

◆ Ensuring that a diverse range of service users are involved, prioritising those who face additional discrimination or disadvantage.

◆ Using Community Development approaches to the work - the values of Community Development include social justice and equality

◆ Developing innovative approaches to involvement work.

Most of our work is supporting ongoing groups, regularly involving over 150 people.
We support:
◆ Three Reference Groups: mental health service users and carers, disabled people with physical and sensory impairments and older people. These groups send representatives to Modernisation Teams responsible for implementing National Service Frameworks in Leeds - ‘Local Implementation Teams’ to use the national jargon.

◆ The Equipment Users Group sends representatives to the Integrated Equipment Services Partnership Board.

◆ The Disabled People and Diversity Project supports the Black and Minority Ethnic Disabled People’s Consultation group, and Rainbow Ripples - a Lesbian, Gay and Bisexual disabled people’s group that is currently carrying out some research into needs that will be of national significance.

◆ Five locality groups whose boundaries mirror those of Primary Care Trusts and council Area Management Teams. These groups are having an impact on improving local mainstream services such as transport, health centres and leisure facilities.

◆ The citywide "Alliance of Service Users and Carers" works on generic issues, which have recently included charging for services and changes to eligibility criteria for adult social services.

As well as group work we provide accredited training on involvement, advice on involvement and carry out time limited projects. At the moment we are working with the Commission for Social Care Inspection on a pilot to involve mental health service users in the Performance Assessment of Social Services Departments.

With a staff team of 9 (not all full-time) plus some freelancers and a turnover of over £350k, we know that LIP is relatively well resourced. There are always challenges in maintaining our funding and a high demand for our services - we still have to turn down many requests to carry out work.

To find out more or to contact LIP visit www.leedsinvolvement.org.uk
Address: Block D, Mansion Gate Drive, Chapel Allerton
Leeds LS7 4SU
Telephone: 0113 307 3280
Email: info@leedsinvolvement.org.uk
Minicom: 0113 307 3282
A
doption of Black children by white families has been known in the UK for over fifty years and yet the voices of transracially adopted children and adults are rarely heard. This UK publication gives voice to the experience of transracial adoption through poetry, art, autobiography, memoir and oral testimony from over 50 transracial adoptees, aged between 6 years and 56 years. The first of its kind in the UK, this ground-breaking collection includes contributions from adoptees born in England, Scotland, Ireland and Wales, as well as those adopted from other countries: Cambodia, El Salvador, Hong Kong, Indonesia, Kenya, Korea, Singapore and Sri Lanka.

In search of belonging conveys the complexity of being raised by a white adoptive family both as children and as adults, demonstrating unequivocally the lifelong impact of transracial adoption. Further, it illustrates that to view transracial adoption in terms of being either a positive or a negative experience is far too simplistic. The range of experiences described within the pages are wide-ranging, including, for example, racism during childhood, placement disruption, visiting country of origin, reclaiming cultural heritage, searching for birth mothers, fathers and other relatives, becoming a parent, involvement with the psychiatric system and connecting with other transracial adoptees. The book is divided into a number of sections covering: separation and loss, childhood, who am I?, reconnection, search and reunion, lifestories, and living with transracial adoption. The themes of loss, and searching for roots and belonging lie at the heart of much of the writing.

This edited collection brings together established writers, such as the poet and novelist Jackie Kay with new and emerging writers, and those who have never before been published. The book also includes a comprehensive resource section of published material by transracial adoptees.

This collection is for all transracially adopted young people and adults - today, tomorrow and in years to come. It is hoped that reading these words will bring comfort, strength and reassurance that we are not alone. Breaking the silence that surrounds the experience of transracial adoption, from the perspective of transracial adoptees, this work is a testament to the resilience and strength of these individuals.
of transracially adopted people, is vital, as is sharing our stories of struggle, healing and survival with each other.

The book will also be of interest to other adoptees, birth relatives, adoptive parents, prospective adoptive parents, social workers, counsellors, therapists, mental health and other professionals.

A launch event was held in May by the British Association for Adoption and Fostering in London. This event provided an opportunity to hear readings from the collection and for transracial adoptees who have contributed to the book (and others) to meet one another.

The editor, Perlita Harris, is a transracially adopted adult who reunited with her Papaji and paternal extended family in 1983, and later with her younger maternal siblings and maternal extended family. She is a qualified social worker who specialised in adoption support prior to undertaking a PhD in Social Work at the University of Warwick. Perlita is currently employed as a lecturer at the University of Bristol, School for Policy Studies, where she teaches on the qualifying and post-qualifying courses in social work. She may be reached at: Perlita.Harris@bristol.ac.uk Tel: 0117 954 6726

Title: In search of belonging: Reflections of transracially adopted people
Editor: Perlita Harris
Paperback 400 pages (May, 2006)
Publisher: British Association for Adoption & Fostering (BAAF)
Available from BAAF tel: 0207 421 2600 or www.baaf.org.uk price £17.95
In search of belonging may also be purchased at a discount through www.amazon.co.uk
**Who or what has had the greatest influence in your life?**
My partner Suzy and our daughters. Without them I wouldn't have been able to keep going.

**What is your most treasured possession?**
This is a difficult one. I have thought hard about it and I guess it is our house in Norwich. All my life I never owned a home. We were poor for a long time and never had enough money. Sadly my sister died in 2000 and left us her money and that meant we could buy a home to live in, with a garden, stairs - the lot!!

**If you had one wish, what would it be?**
Apart from health, happiness etc, do you mean? To win the lottery, then with others I could get on with the work we want to do instead of permanently having to be begging for money!!

**What, if it were up to you, would you ban?**
Privatised railways and cheap air flights, then they'd have to have more rail and sea journeys - which I can cope with!

If you could change one thing in health and social care services what would it be?
I’d make them truly user controlled and rights led so that people could have the support they want and need.

What makes you laugh?
Harry Hill and definitely NOT Jimmy Carr.

What trait do you like least about yourself?
My anxiety.

What trait do you most dislike in other people?
Endless conversations about Big Brother and the like.

What is your idea of perfect happiness?
Sitting in a café, able to dream away, while watching all the folks go by.

What is your favourite film or television program?
Film: All Quiet On The Western Front - because it told the truth and current TV favourite - Life On Mars - all the fun of the seventies and now.

What has life taught you?
Just try and keep going.

How would you like to be remembered?
As Peter Beresford who led a life of great achievement until tragically cut short in good health on his 110th birthday with his partner, children and grandchildren all around him.
We thought it would be inspiring to find out what it is that makes people feel happy....so we asked them!

Meeting friends and being more confident

Taking time to smell the flowers

Singing!

Doing yoga

Drinking a large fruit smoothie

Wearing nice clothes on a hot sunny day

Finding a junk shop with bargains in it especially if it sells books

Lying on grass in sunshine

Being myself and being confident and being happy in love

I think about the people I love

Reading a positive black book

Walking on a wild and windy day on a deserted beach

Seeing my grandchildren

When the cat decides having a stroke is far more important than what I’m doing on the computer, and sits on the keyboard until I oblige him.

Answering all my emails

Seeing my grandchildren

Take time to smell the flowers

Lying on grass in sunshine

Doing yoga

Drinking a large fruit smoothie

Wearing nice clothes on a hot sunny day

Finding a junk shop with bargains in it especially if it sells books

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**Pills and Potions**  
A poem by Patricia Chambers

Pills and potions  
to control my emotions  
A medication deal  
to restrain what I feel  
A drugs cartel  
to make me feel well

Despite all this and research it's still not understood  
That that's not what I need to make me feel good  
Uppers and downers to get me through the day  
And all the time I'm thinking there's got to be another way

Muscle relaxers to stave off the side effects  
Temporary relief and weight gain's the only thing I get  
I'm always on a diet watching what I eat  
A three course meal's an almost unheard of treat

Procyclidine, Lithium and Olanzapine  
all part of the psychiatric keep them coming dream  
Unseen and repulsive they're secretly giving you death  
And they'll keep you coming until your last breath

They won't take heed  
it's not what we need  
They don't care what they do  
to the likes of me and you

Pills and potions  
To control my emotions  
P.C. 2005
Peter Beresford and Mary Nettle, both mental health service users/survivors, are carrying out a small national project supported by the Joseph Rowntree Foundation to find out more about what people with experience as mental health service users/survivors think about mental health issues. They are trying to find out more about what kind of models, ideas and frameworks mental health service users themselves use to think about mental health issues.

This parallels the work of disabled people in developing the social model of disability. What do mental health service users find are helpful ways of thinking about mental health issues? Do they use different ideas and models to those used by professionals, in policy and by the public generally? What do they think of more social and holistic approaches to understanding mental health issues? Do they see mental health issues in terms of an individual illness, or do they think, for example, that they need to be understood in terms of broader barriers and discrimination?

If you would be interested in taking part in a survey or perhaps a group discussion about these issues then please contact Peter or Mary by email and we will send you more information. Your views would be treated in strictest confidence and you would remain anonymous, but be kept in touch with the findings from this user controlled study.

peter.beresford@brunel.ac.uk
MaryNettle@userconsultant.freeserve.co.uk

or write to Peter at:
OSP
Tempo House
15 Falcon Road
London SW11 2PJ

Many thanks and hoping to hear from you.
Shaping Our Lives has lead responsibility for this project, which is supported by the Joseph Rowntree Foundation. We have been told that this is probably the biggest project they have ever funded! The aim is to help service users get the support that they want and find ways of finding and overcoming the barriers in the way of them getting it.

We have now made first visits to all the eight places and partners which are involved in the project and begun to find out more about them and get to know them.

One big problem we have had is that to get what is called ‘ethics approval’ our goal of meeting with service users from the very start, hasn’t been possible in all cases, because you are not supposed to do that until that approval has been given.

We want to highlight that this is a big problem and a barrier which must be changed, if service users are really to be involved from the very beginning.

There will be more about this project in the next newsletter so we can keep you in touch with developments.

‘Spoiling our fun!’
cartoon courtesy of Crippen

“You do realise that by not being grateful you’re spoiling all of our fun!”

We welcome contributions of creative writing and illustrations for the Shaping Our Lives newsletter. Please get in touch with us if you have something we could include.
Mayo Marriot tells us about ILA PA Services which provides both information and Personal Assistants (PAs) to enable disabled people to live independently. PAs assist a disabled person to live independently by following the instructions of the disabled person to carry out any reasonable daily tasks.

ILA is a not-for-profit company. ILA is managed and controlled by a Management Committee made up of six ILA Service Users. David Morris, a prominent figure in disability, is the Chair of this Committee. Tracey Jannaway, has over 15 years experience as the Director of ILA. ILA defines success by:

- the high-level of user involvement in the organisation
- low levels of placement breakdown
- responding flexibly to individual need and adapting to change
- 60% of PA users have used ILA for 10 years or more
- 91% of PA users & PAs use ILA because of its user-led philosophy.

PA Services is funded by the Bridge House Trust and the Esmeé Fairbain Foundation to work across London recruiting PAs. PAs are usually employed directly by the PA User and can work as little as a few hours each week or on a full-time basis. The other main benefits of PA Services are:

- By pooling resources advertising budgets can be affordable
- Advice on any aspects of recruiting and managing PAs
- Short-term cover provided by experienced PAs trained by disabled people
- Established by disabled people who use personal assistance

Please mention PA Services to anybody you think may benefit, it's free to join! We are willing to answer any individual questions and give presentations tailor-made for Organisations and User Groups.

For more information contact:
Independent Living Alternatives
Trafalgar House
Grenville Place
London NW7 3SA
Tel: 020 8906 9265,
Email: PAServices@ILAnet.co.uk
Web: www.ILAnet.co.uk
Shaping Our Lives National User Network is a national user controlled, independent organisation 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.

Who do we work with?
We work with a wide and diverse range of service users. We do not discriminate on the basis of race and ethnicity, sexual orientation, gender, age or religious belief. Here are some of the people we work with:

◆ young people with experience of being ‘looked after’
◆ people with physical and/or sensory impairments
◆ people with learning difficulties
◆ people living with HIV/AIDS
◆ people with life limiting illnesses
◆ users/survivors of mental health services
◆ older people
◆ people with experience of alcohol and drug services

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 world wide international user controlled organisations

Shaping Our Lives Newsletter
If you have something you would like to see included in the next Shaping Our Lives newsletter please get in touch. Thanks to everyone who sent contributions in for this edition. We are sorry that we can’t include everything we receive. Please feel free to contact us with comments on articles in the newsletter, and suggestions for future editions.

This newsletter is available in different formats on request.

Anyone wishing to reproduce articles should contact Shaping Our Lives for permission. the views expressed in this publication should not necessarily be taken as Shaping Our Lives policy. Every care has been taken to provide accurate information but Shaping Our Lives, the Management Group and staff cannot take liability for errors or omissions.