

## FRONT PAGE

# VOX Grows...Welcome to John and Mahmud!

As you may be aware VOX was successful in being awarded £240,000 from Comic Relief over the next four years, this has allowed VOX to recruit two new members of staff, John Steel who is our Administration Officer and Mahmud Al-Gailani who is our Diversity Facilitator. We would like to welcome our two members of staff and I'm sure you will have the opportunity to meet John and Mahmud over the coming months. This will mean that VOX will now be able to reach out to more of our members, and to develop a range of new initiatives. You will hear more from John and Mahmud in the next edition of VOX.

### **Moving towards independence**

From the outset when VOX agreed that they would like to become independent, we have been hosted by the Mental Health Foundation which has been fundamental in supporting VOX to become a sustainable, independent organisation. The VOX board are working on an independence timeline which will allow us to move towards independence. We are currently working with solicitors, developing our financial systems and developing policies and procedures to make independence a reality, we will update you with our progress; staff will be seconded initially to ensure that these changes are phased.

### **VOX bi-annual members meeting**

The bi-annual meeting of VOX members will be held on Saturday 6<sup>th</sup> December 2008 in The Millennium Hotel George Street Glasgow from 10am until 3.30pm. This provides a good opportunity to hear more about the work of VOX, and to let us know if you think we are focussing on the right areas of work.

The agenda is as follows:

10.00am – 10.30am	Registration, Tea and Coffee
10.30am – 12.30pm	Presentation on "What we are doing"
12.30pm – 1.30pm	Christmas Lunch
1.30pm -- 3.30pm	Members Views

We will write to members nearer the time with further details.

### **MWCS Tribunal Experience Survey**

The Mental Welfare Commission for Scotland is conducting a survey of service user and carer experiences of the Mental Health Tribunal for Scotland. Every service user or carer who attends a Mental Health Tribunal in Scotland from 20<sup>th</sup> October to 17<sup>th</sup> December will be given a survey **questionnaire** which will allow them to share their experience of their Tribunal. It is important that people who have been through a tribunal process are able to tell the Mental Welfare Commission what it is like for them so that they can see if there needs to be any changes that would make the tribunal system work better for those involved. We would encourage any of our members involved in this process to respond to the questionnaires.

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# Voices Of eXperience

## MEMBERS PAGE

We wish to give members the chance to share their views with other members. This can be in the form of stories, creative writing and poetry, on any topic related to mental health that you wish to discuss. Please send your articles to VOX c/o Mental Health Foundation (Scotland) Merchants House, 30 George Square, Glasgow G2 1EG or email: [wmcauslan @ mhf.org.uk](mailto:wmcauslan@mhf.org.uk) Remember to mark clearly if you wish to remain anonymous.

# AskClyde

## MORE THAN RESEARCH AND CONSULTANCY

What's a social firm? You may have heard of the term social firm and wondered what this mean, in this edition we are going to look at AskClyde a social form based in Clydebank.

AskClyde provide a variety of research and consultancy services include Market Research, Evaluation Services, Business Planning, Feasibility Studies and Impact Assessments. AskClyde deliver this contracted work across the public, private and social economy sectors.

However, AskClyde is more than just a research and consultancy company. It is an emerging social firm, providing employment, training and volunteering opportunities for people recovering from mental ill health within the West Dunbartonshire area.

AskClyde offers quality volunteer placements that help people develop routine and structured work activities in a supportive, creative working environment. By providing transitional support we allow our volunteers to expand and strengthen key coping skills and resources that assist them on their road to recovery.

## PAGE TWO

### Music United

VOX can unite in the harmony of song  
In holistic music where we can all belong  
So are you ready the places  
So are you ready the places  
Lets join in lets go  
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What use is wealth?  
If we don't have our mental health  
Let's shake these problems away  
And wake up to a new happy day  
Music think, music play  
Clear your mind the music way.

## **Art Therapy**

Work those negative feelings out through art  
So that anger and frustration will soon part  
Splash those dark moods about  
Let the bright colours venture out

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Don't matter if your talents raw  
You can learn to paint and draw  
Splash happy colours about, let it flow  
Let dark frustration and anger go.

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#### **Recovery by Jason Smith**

I hope by telling you part of my life story I can help you save some time and effort building a different life for yourself. I had to leave my old life and experiences behind me, which included my family; this meant me having to change my house, career, friends, memories and surroundings so that I could move on in my life. All these changes have helped me develop a deeper awareness and understanding over the years of my recovery. I have found reason and meaning in my life. We all need to find our own solutions, there are different paths, and the trick is taking the right direction. I had to create for myself a recovery plan which was simple and easy to use to reduce my anxiety and stress levels.

I enjoy team work the most; the company, sharing skills and combining experiences, I see it as individual people supporting each other in a crisis and getting through it together, it challenges and rewards at the same time, and to me that's friendship, companionship is a big part of that. I've continued to build bridges that bring me closer to others and help me become part of the fabric of their lives. This bonding makes me feel included; part of the "family".

After some time spent struggling with life and circumstances, I realised that I needed some help from doctors. I had a lot of big choices and decisions to take before my recovery could start, family and friends can sometimes hinder rather than help. I chose to do what was right for me; it took time and effort to begin to achieve changes, gradually turning old habits into new, more positive patterns of behaviour. I'm still changing and moving towards recovery, every day in my life in fact, I take each day as a challenge to rise to.

As I grow and mature, so does my recovery plan, it's getting very multi-layered now and allows me to cope with new developments, my routine (like a bus timetable) helps me keep on track and motivated, I can take control back in my own hands.

All this has taken me twenty years to achieve; I view every day as a new experience that I can look forward to. In short, my journey along the road to long lasting recovery has been all about hard work, perseverance and patience; I have learned my lessons from my past mistakes and have changed my whole life around.

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## *Be seen as a person first, the illness is a part of your life, not your life*

### **Dementia – a National Priority**

Dementia is the progressive decline in [cognitive function](#) due to damage or [disease](#) in the body beyond what might be expected from normal [aging](#). Although dementia is far more common in the [geriatric](#) population, it may occur in any stage of adulthood.

VOX welcomes the Scottish Governments recent commitment to making early diagnosis and management of patients with dementia a national priority.

From April 2008 each NHS Board is to deliver agreed improvements in the early diagnosis and management of patients with dementia by March 2011. Each NHS Board is now responding to a target increase of 33%

There are a range of initiatives looking at improving services, this includes ensuring that there is a set standard of care, this will be developed through what are called integrated care pathways - basically pathways of care (from a range of organisations), which makes sure that there is a robust and clear system for the service user.

For dementia this will include ensuring that treatment for cognitive impairment is recorded, that interventions match the needs of the service user, and that advance planning is in place in relation to end of life care.

Other developments include the Mental Health Collaborative for Dementia which drives and supports the targets which have been set.

Information has also been developed, coping with Dementia - a Handbook for Carers has been updated and a guideline on the provision of information to people with dementia and carers throughout all stages of their journey is being developed by the Information Guidelines Working Group.

There have also been a National Conference on Dementia Awareness in Children. This conference explored the training and care needs for children undergoing changes similar to those associated with dementia.

There are many other pieces of work also happening which are all aimed at making Dementia a national priority, VOX are involved in the Dementia Collaborative and are keen to hear your views on what you think should be focused on in this important area of work.

### **A song by James McKillop**

Just look through my eyes  
And then surely you'll see  
The spirit of the person  
Still deep down within me  
But when I'm looking outwards  
I' still me despite being, so much  
Differently The Same

Mmm-Mmm things easy before  
Can be much harder now  
A-a fond memory sought  
Will furrow my brow  
Amidst all this turmoil  
Doggedness enables me, to cope  
Differently The Same

I am still your friend, from your far off schooldays  
Your ever-loving spouse ever since our wedding day  
I'm still your father, your mother who  
Was forever there when you were needed most  
I'm your big sister, your little brother  
I' the person who needs all of your understanding  
Though things inside me are changing  
I still love you all though I've become  
So Diff'rently The Same

Odd looks come my way  
When I fail to disguise  
A feeling lost expression  
That comes clouding my eyes  
But what's the alternative  
To sitting housebound feeling, sadly  
Diff'rently The Same

Mmm-Mmm friends of bygone years  
Don't know how to react  
Some speak past me in hushed tones  
Others have less tact  
And fidget in my presence  
Yet someday they might also, become  
Diff'rently The Same

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### “Employability”

A focus group was held on Tuesday 14<sup>th</sup> October to discuss a response to the government's new Green Paper document on Welfare Reform titled “No - one written off; Reforming Welfare to Reward Responsibility” The Green Paper makes proposals and announcements, some of which are detailed below.

- The migration of **all** existing Incapacity Benefit recipients onto the new Employment Support Allowance
- A reassessment of capacity to work for **all** recipients of Incapacity Benefit during the migration to ESA (Employment Support Allowance).
- Increased benefit (£102.10 a week compared to £86.35) for those ESA recipients assessed as having the most severe disabilities and health conditions. A focussed return to work programme for those with less severe issues.
- Job Seekers Allowance for those seeking work and carers.
- Employment Support Allowance for the sick and disabled who cannot work.
- Suspension of benefits for those who persistently fail to attend appointments and interviews.
- The statutory medical certificate system will be reformed with a view to reducing the risk of individuals with health conditions becoming detached from the labour market.

There was a consensus among those present that this consultation document was “inaccessible” and very difficult to get a clear understanding of what it means to service users therefore the discussion centred around four key questions in particular:-

**How we might build on the foundations of the current rules so that they do not discourage unemployed people from volunteering as a deliberate back to work strategy. Some of the comments made by the group were:**

- People worry that if they volunteer then they can work full time!
- The £20 disregard is demeaning and humiliating, people should be encouraged to volunteer without sanctions.
- People are reluctant to volunteer as they may be seen as “employable” and either forced into work or removed from benefits (penalised)
- There needs to be consideration that people may not be turning up for Jobcentre appointments due to a sudden deterioration in their mental health, and these appointments may be ones when non attendance is penalised.

**How can we make Access to Work more responsive to the needs of claimants with fluctuating conditions, including mental health conditions?**

- Should be a simple way back to benefits if one finds that they cannot work.
- Social Firms are the way forward for people with difficulties, disabilities and recovery from mental illness, supportive environment, training, voluntary full time or part time.
- Something should be available for people to “Dip their Toe” to see if they can succeed at work.
- Needs to be as easy as possible to move from benefits to work and back again.
- Ongoing support with less or no sanctions.

**What additional flexibilities in the system, or forms of support, would claimants with multiple and complex problems need to enable them to meet the new work-focussed requirements proposed in the Green Paper. What are the barriers and what support would be required.**

- |   |   |
|---|---|
| <ul style="list-style-type: none"><li>• <b>Barriers</b></li></ul> | <ul style="list-style-type: none"><li>• <b>Supports</b></li></ul> |
| Telling employers   | Recovery plan   |
| Stigma  | Appropriate training  |
| Dead end jobs   | Social firms  |
| Therapeutic earnings  | Peer support  |
| £20 disregard   | Job placements  |

**Do you agree with the proposed approach for identifying problem drug use, how this should be implemented? Do you think that everyone claiming a working age benefit should be required to make a declaration on whether or not they use certain specified drugs?**

- Violation of Civil Liberties
- Violation of Human Rights
- Dual diagnosis
- Stigma of disclosing

## **Summary**

VOX decided to take a different approach in consulting our members from what was suggested in the document. The approach we used highlighted some key themes around the need for flexible systems, the importance of the right kind of work, the assessment procedures and, the level of understanding those who undertake the assessments have of mental health.

In addition to this, the value of volunteering, and the fact that it's not always an in between stage (work isn't appropriate for everyone. The working environment must also be considered, there is still the lack of

understanding of mental health within the workplace. It was recommended that more flexible approaches are required to support people and that the responsibility is not solely with the individual.

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### **HOT TOPICS**

#### **“Volunteering/Service User Involvement”**

Volunteer Remuneration; should there be some kind of remuneration for voluntary workers?

What kind of personal benefits do volunteers get? Here are some quotes:-

- “I am currently involved with Cancer Research as a volunteer and am doing a retail course for which I hope to attain an SVQ, it has been a rewarding and positive experience”
- “My previous work history being secretarial and administrative work, it has been a great opportunity to work in an office again and update my skills. Due to the supportive environment, I have grown in confidence to seek full time paid work”
- “I was bored sitting at home every day with no one to talk to; a volunteer’s experience really depends on the individual and also on the type of voluntary work undertaken. I would give anyone interested in volunteering an incentive to volunteer, like an extra £20 a week”
- “If the plethora of documents surrounding current and new initiatives in the mental health field are read, one cannot avoid the repeated need for service user involvement: the Lived Experience. That this is the case is refreshing to see but I fear that the contribution of the service user is in danger of being under-valued because the issue of remuneration is not being treated seriously enough. The receipt of benefits is repeatedly given as a stumbling block when remuneration is brought up. I was made aware of the danger of not disclosing additional income but the decision to do so or not, was left quite rightly, with me. Benefits are a mine-field that many service users have to cross, and advice is often required, but the receipt of benefits, in my view, ought not to be used as a reason to withhold payment for contributions. When a contribution is worthy of remuneration, is it acceptable to expect it to be *gratis*?”
- “As a service user I “worked” for seven years as a volunteer, treated it as a full time job and never once did I feel that I should be paid for doing what was not only beneficial to that particular service, but the most important fact was that in doing so I had the most benefit of all, learned new skills, gained self worth and self respect, these were of course additional benefits which clearly outweighed any kind of remuneration, one could not put a price on these benefits”

#### **Service User Volunteers - To pay or not to pay?**

“There seems, at the moment, to be an ongoing discussion about whether or not service users who volunteer to do some large and important pieces of work should be paid.

How do we pay people without it affecting their benefits, and how much? All payments over and above the benefit level should be declared to the Department of Work and Pensions, otherwise the service user risks breaking the law. The DWP will deduct the money earned from weekly/fortnightly benefits, and it can take more than a fortnight to have the original benefit restored, which is stressful in itself. Even very small expenses, say a payment of £2.50 a day for lunch, or for travel, if you do not have a bus pass, can be counted as unearned income by the DWP.

Rewarding volunteers for their time by giving them gift vouchers is, quite literally, tokenistic, and although I can see the reason behind it, i.e. to acknowledge the time the volunteer has given, it is no more than a gesture. The experience of service users is of vital importance, particularly when developing mental health training for groups such as student nurses, and also where formulating policies is concerned.

Payments, and quite substantial ones, should be made where the service user is acting as a consultant, and is giving of their time and knowledge in order to improve services and combat the stigma which surrounds mental ill-health. However, there is also the fact that most people who volunteer do so because they wish to give something back to the community, and do so without expectation of reward, although some sort of acknowledgement is nice.

There is also the impression, at times given by the DWP, that if you are fit enough to volunteer, then you are fit enough to return to paid work – which is not always the case. A couple of hours or days a week as a volunteer may be just enough to maintain good mental health, whereas full-time work, which may have been the cause of the illness in the first place, may be detrimental to the volunteer's health.

So, what do we do? How do we acknowledge the time and knowledge the service user gives to the organisation for which they volunteer? Perhaps volunteers should be allowed to earn so much in a year in consultation fees without it being registered as unearned income for the DWP. With the new Employment and Support Allowance now in place, the question of payment for time and experience may be fraught with even more difficulties.

In conclusion, I feel that some sort of cash payment should be made in cases where a substantial amount of time and/or experience has been given by the service user, but in other cases, it should be left to the discretion of the organisation.”

**Robbie Campbell**  
**Research Volunteer**  
**Mental Health Foundation and member of VOX**

## **BACK PAGE**

**If you need to talk to someone call the following numbers:**

**Samaritans**  
**08457 90 90 90**

Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

**Breathing Space**  
**0800 83 85 87**

24 hours at weekends (6pm Friday - 6am Monday) and from 6pm to 2am on weekdays (Monday - Thursday)

**NHS 24**  
**0845 4 24 24 24**

An online and telephone-based service, which can answer your questions about your health and offer advice.

## **GROUPS CAN NOW JOIN VOX**

Local, regional and thematic service user led mental health groups can now join VOX, this is a great opportunity for all of us to stand together to make the voice of those who have, or have had, a mental health problem stronger. For more information and membership criteria please contact Wendy on **0141 572 1663** or e-mail [wmcauslan@mhf.org.uk](mailto:wmcauslan@mhf.org.uk)

### **Are service users really involved in planning mental health services?**

Have any of our members been involved in the planning or design of a new mental health hospital? Here is an article from David Atiyah.

“At any one time there are probably several new mental health hospitals being planned or built in Scotland, partly because it is such a long and complicated process. With the Scottish Government keen to make sure they get value for money the NHS has to involve patients or else permission will not be granted. But as anyone who has tried to participate and contribute will tell you; the cards are heavily stacked against us.

The Government lays out the guidelines that each local NHS Authority is required to follow the **Scottish Capital Investment Manual** (SCIM). This document is about the size of an encyclopedia and is definitely not recommended reading for VOX members; it is currently being revised and has gone to public consultation. It is worth stressing that NHS Lothian is not the only health board planning a new mental health hospital, there is no central list but I know that both Perth (Tayside) and Larbert (Forth Valley) are well advanced in Scotland, and there may well be more. If you have been, or are currently involved in the planning of a new hospital, do please consider attending our members meeting in December, Service Users should try and meet to share experiences”