

Glimpses of peace

by

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Trauma can be the main trigger or cause of voice-hearing in many people. In this paper, Sharon de Valda evocatively conveys how racism and sexism shape her experience of hearing voices and how she has in turn used her own experiences to assist other voice-hearers.

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My name is Sharon de Valda. I am thirty-nine years old and I live in a small flat in Manchester with my husband Mickey and our pet cat. I have been a voice-hearer since I was aged thirteen.

I became a volunteer at the National Hearing Voices Network a good few years ago. I first attended their self-help groups along with Mickey. At this point my life was rather disturbed and my voices made me feel suicidal and hopeless. I later discovered that, thanks to Mickey's constant support and care, I was changing gradually. I was slowly moving towards recovery. Recovery is the big buzzword in mental health at the moment, previously we were never expected to get well again. I have met many different people at the Network and am now in the position of being able to give help and guidance to other voice-hearers. In a strange way, helping others has contributed to my own journey of recovery.

Trauma can be the main trigger or cause of voice-hearing in many people and I'd like to give you a brief introduction to my childhood. I was abandoned at birth by my

white mother for one reason – simply because I am black, of mixed race. My mother may have wanted to keep me, but it was impossible as I was illegitimate and her husband at the time refused to keep me with his other children. My natural father (who I cannot trace) was black. So I had to go into care, and ended up in the authority of the charity Dr Barnados. I endured much racial abuse at school. As I lived in a white area, people stared and I grew up paranoid and lonely. Other children's parents told them to keep away from me. I became withdrawn, confused, sad and suicidal. The first time I can recall hearing voices was when I was thirteen years old. The voices terrified me. They ordered me to kill myself; they were so persistent. They called me 'nigger', 'coon' and 'wog'. Sometimes it was like going to a football match and being the only black person. It was like standing in the middle of the field and everyone in the crowd was white and was shouting racist names at me. That's what it was like. I moved from the children's home to foster homes, from foster homes to prison, from prison to hospital. It was quite a trip.

I have grown to accept and understand that my own voices are 'flashbacks' of memories of horrible racism that I experienced as a child that have become imprinted in my memory. Since I now accept this fact I have developed my own coping methods. Now I try to handle the racist voices by rationalising that the shaven headed men in the pub will not beat me up, they might not be racist skinheads, but simply balding men or football supporters. Sometimes it is hard to realise this and at other times it works well and gets me through.

Women's stories

In recent years I have acted as a facilitator for Hearing Voices groups, especially for other women. I think it's important that as women we have a chance to speak with one another about our different experiences. It can be helpful to have other women to share stories of abuse for instance, and to help get rid of the guilt we might feel about it. Women shouldn't feel this guilt about abuse we have experienced, but it happens. It can manifest itself as a voice that calls us demeaning words like 'whore' or 'bitch'. It might be the voice of the abuser and it comments upon how we are as a person, how we're dressed or how we're acting. It might say things like 'you're a slag', if you'll excuse my language. The voices make these sorts of comments. And if we talk as women about these things it can be really helpful to hear that others go through similar things. You then feel like you're not the only one and this can create a sense of kinship.

Self-harm is another big topic that we talk about. Sometimes the voices tell you to harm yourself, and sometimes self-harm is actually a coping strategy. It is a taboo topic and it is complex, so it means a lot to be able to talk with others about it. The voices sometimes order me to scratch my face, and to harm myself in other ways. But the physical pain can actually come as a relief. It reminds me that I am real. It's a way to focus the hurt physically. I know that sounds a bit mad but it is true for me at times. When my arm is actually bleeding it's almost peaceful.

We talk about all of these things in the groups. One of the issues we also have to address in the groups is when people make jokes about gay people, or racist jokes, jokes about Irish people, or jokes that are negative about women. I have never understood why some people find these things funny. It genuinely confuses me. Sometimes I have been in a group and sat there thinking, am I supposed to laugh now? Sometimes you have to laugh 'cause if you don't you get ostracised. There are

some very strange ideas out there in the world. For instance, it seems that some people will be my friend if they can make racist jokes about me. I'm very interested in how being black and being a woman affects the voices I hear. I'd also like to know what difference it makes if you have a disability, or if you are gay. Do the voices play on that too?

Recently, I have done some work in a woman's prison. I didn't do a lot, but I identified with the women there. I was locked up myself years ago and actually, because I didn't have a family or anywhere else to go, I didn't mind it that much. I accepted it as a place to live. The women I met with recently though, were very young and naïve. Some of the women had never talked to anyone about hearing voices. I remember one woman was really harming herself and we tried to talk about different coping strategies. It must be pretty hard sitting in a cell hearing voices and not having anyone to talk to about this. I think there should be more opportunities for voice-hearers to go into prisons and meet with people inside who are hearing voices, to show them some understanding. It could save heaps of people from going through even worse experiences. It's not right to leave people just to cope for themselves.

Depression

In the last few months, I have felt like I've been imprisoned inside my own head. I have been experiencing profound depression. People are often more interested in talking about the voices than depression and I find depression more difficult to describe. You might find it hard to understand why someone might lie in bed all day. While they may not be hurting on the outside, they're hurting inside. It is like an overpowering sense of hopelessness and despair – a wishing that you were not alive. This depression has had me feeling completely trapped. It's a strange sensation because it also feels sometimes as if I am looking down at myself, as if I am separate from my own body.

I think the voices make me more vulnerable to the depression. The voices are so negative that they bring me down. If I wasn't hearing the voices, I might feel more like doing things. But when the depression comes it seeps into my body. It takes me over and confines me to the bed. It's as close to hell as I could ever imagine. While it might look as if I am just being lazy, I am actually living a hell. The phone might ring right next to me and I am unable to pick it up. I know it sounds strange but it is true. I would like to find

other people who have had experiences of depression, so we can make notes together, find words to describe it. I'd like to hear about other people's coping strategies. Sometimes having a bath can be good. Or even just getting up to have a cup of tea. If anyone is interested, I'd like to hear from other people who have experienced depression and perhaps together we can find out what to do.

From all the experiences I have had, I have learnt a lot about trust and making connections. I know that I can make really good connections with other people who hear voices. I can also connect well with people who have learning disabilities. I know how to reach out to them. When I have something in common with another person, whether it is experiences of racism, or voices, or being in prison, we can find ways to trust each other differently. When I meet someone who is vulnerable, or who does not find it easy to trust, I try to find something we have in common. I am open with them, and ask about the content of the voices. The voices they hear might say similar things to what mine do and then we can talk about how we cope with this.

One of the ways in which I try to escape is that I have put pictures up all over the walls of our lounge room. They are all pictures that tell a story of a good time, some precious memory. There are so many photographs, clippings, and pictures. The amazing thing is, when I eventually found my mum and I went into her house for the first time, I saw that she does the same thing. It was quite extraordinary. Her walls are also covered with pictures, almost every square inch of the house, many of them of old film stars. I felt like I had gone home, even though I'd never lived there. Not only this, I discovered that our facial expressions are quite similar.

Now, when I sit in our lounge room and look at all the pictures, there is also a picture of my mother. The room and the pictures and their stories bring me glimpses of peace. But I do so wish someone could find a cure for depression.

Thank you.

Note

1. Sharon de Valda facilitates groups for the Hearing Voices Network in Manchester, UK. In 1994 Sharon and her partner, Mickey de Valda, featured in a ground-breaking video called 'Mad, Bad or Sad' shown on BBC 2. Sharon can be contacted c/o HVN 91 Oldham St. Manchester M4 1LW. Tel: 44-(0)161-834 5768. Fax: 44-(0)161-834-5768 Email: info@hearing-voices.org

Other developments in the 'survivor' movement

The work of the Hearing Voices Network is linked to a range of other developments in 'psychiatric survivor movements' that are occurring in the UK and elsewhere. We have included here just a few examples of this work:

Mad Pride

Mad Pride (www.madpride.org.uk) organises concerts, festivals and campaigns celebrating the resistance, humour and lives of people with mental illnesses. It is committed to ending discrimination against psychiatric patients, promoting survivor equality and celebrating 'Mad culture':

Mad Pride – the equivalent of Gay Pride for people who have suffered mental ill-health – has truly arrived. There have been Mad Pride gigs ... Mad Pride marches and Mad Pride demos; there is a Mad Pride website, a forthcoming Mad Pride anthology and there are even plans for a Mad Pride Week ... Mad Pride is different because above all, it wants to change the way in which society views people with mental health problems ... using a classic civil rights tactic to combat ... misleading stereotypes, Mad Pride takes the label with a negative value ('mad') and reappropriates it. 'Glad to be Mad' is its slogan. (Seaton, M. quoted in British Psychological Society Division of Clinical Society 2000, p.57)

Survivor workers

Within the UK there is also a growing community of survivor workers who held their first ever national conference in 2002 (see Snow 2002). Not only are such forums providing support for those people who have had experiences of mental health difficulties and are now working in the field¹, but they are also creating a momentum which is questioning taken-for-granted notions about the nature of professionalism. Inspired by the example of Dr Rufus May, Dr Rachel Perkins and other health professionals who have 'come out' about their previous psychotic experiences or mental health difficulties, different conversations are now becoming possible. Perhaps before too long health professionals will be able to openly discuss their own experiences of mental health difficulties and how these experiences shape their work. [PTO]

Dr Rachel Perkins' work with the Pathfinder User Employment Program is actively campaigning to remove obstacles for employment for people with mental illnesses.

[The Pathfinder User Employment Programme] ... is a program designed to increase access to work within mental health services for people who have themselves experienced mental health problems. It looks at mental health services not as providers of service, but as employers – I believe that ... the National Health Service is the largest employer in Europe – 1 in 20 of the working population is employed by it. It recognizes the employment discrimination that people with mental health problems experience in getting jobs in mental health services. But this is not altruism – helping the poor unfortunates. Instead it is helping the poor services. The programme was founded on the belief that the expertise of experience is essential to the provision of mental health services that are actually useful to us ...

Well, to date we have provided support to almost 50 people with mental health problems to help them to gain and sustain ordinary jobs ... on the same terms and conditions as everyone else. This is not about creating 'special jobs' for the 'loonies' – it is about jobs in clinical teams and services that already exist ... We have also provided work experience for over 80 mental health service users ... (Perkins quoted in Snow 2002, p.29)

Perhaps even more significantly, Pathfinder has developed a 'Charter for the Employment of People who have Experienced Mental Health Problems' which is designed to decrease employment discrimination. Amongst other things, this Charter requires that employers include 'personal experience of mental health problems' as a desirable qualification for employment in all their advertising of positions, and to work towards a goal of at least 25% of recruits having personal experience of mental health problems.

For more information about the Pathfinder User Employment Programme see:
http://www.schizophrenia.co.uk/policy/policy_articles/policy_articles_4.html

Matters of race

Survivor movements are also trying to address race relations in this work. In the following quote, Dr Rufus May describes one of the workshops he attended at the inaugural National Survivor Workers' conference and why it was significant to him:

Another workshop I attended ... looked at how white survivor workers can support black survivor workers. Culture and mental health is an area in which it is crucial to maintain a focus on social and cultural identity. This seems an important and neglected aspect of the recovery process. For example, of the seven people who were treated alongside myself for psychosis, when I was a patient, whose outcomes I am aware of, the difference is striking in terms of cultural background.

Of the two white people, one is a freelance user/mental health consultant, the other is a journalist. Of the five Black people, two are dead, the other three are on neuroleptic depots, one has Tardive Dyskinesia. The conclusion I draw from this experience is that there are significantly greater social obstacles to recovery for Black people. (Rufus May quoted in Snow 2002, p.47)

Elsewhere in the world

We have provided here just a tiny glimpse of the range of work that is happening in the UK in relation to 'psychiatric survivor movements'. For more information about the work occurring in other countries please see:

- European Network of (Ex) Users and Survivors of Psychiatry ~ www.enusp.org
- The US based Support Coalition International ~ www.mindfreedom.org
- Psychiatric Survivors of Ottawa ~ <http://ncf.davintech.ca/freeport/social.services/opsa/menu>
- In Australia, contact the ACT Mental Health Consumer Network c/o PO Box 469, Civic Sq, ACT 2608, Australia.

Note

1. The report of this conference contains a very helpful section titled 'Good practice guidelines for employers' (Snow 2002, pp.51-52).

References

- British Psychological Society Division of Clinical Psychology, 2000: *Recent advances in understanding mental illness and psychotic experiences*. The British Psychological Society.
- Snow, R. 2002: *Stronger than ever: The report of the 1st National Conference of Survivor Workers UK*. Cheshire: Asylum.