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<th>Journal:</th>
<th>Mental Health and Social Inclusion</th>
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<tr>
<td>Manuscript ID</td>
<td>MHSI-01-2017-0003</td>
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<tr>
<td>Manuscript Type</td>
<td>Case Study</td>
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<tr>
<td>Keywords:</td>
<td>Hearing voices, Recovery, Music, Relationships, Employment</td>
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Shaun Hunt in conversation with Jerome Carson.

Shaun Hunt and Jerome Carson.

Abstract

Purpose – The purpose of the article is to provide a profile of Shaun Hunt.

Design/methodology/approach – Shaun provides a short biographical description of his life. He is then interviewed by Jerome.

Findings – Shaun tells us about the long journey of recovery that he has made to the point where he is now a University lecturer.

Research limitations/implications – In large group studies the individual gets lost in statistical tables and the lived experience is absent. Single case studies provide us with stories to nurture and encourage us all.

Practical implications – Shaun says that we often miss the obvious question in our interactions with people with lived experience. “What happened to you?” seems a simple but telling conversation opener.

Social implications – As Shaun says there are some amazing people who work in mental health services, but they are the ones who spoke to him and not to a “schizophrenic.”

Originality/value – As Shaun also says, “Never, ever give up hope, no matter how dark and bad things become, there is always a way back.”

Keywords Hearing voices, Recovery, Music, Relationships, Employment.

Paper type Case Study

Introduction

Standing at six foot four inches tall, Shaun is not someone you are likely to miss easily. I met him the first time at the Hearing Voices Group Christmas Party in Sheffield and again the following year at the same party. However it was only after I heard him give a talk about his recovery journey at the Hearing Voices Conference in Manchester, that I truly appreciated what a remarkable man he was. He was a wonderful, natural speaker with an amazing story to tell. Here he shares some of it with us...
Brief biography by Shaun Hunt

I was born in 1969 in a small Yorkshire town. It is my belief that my childhood set the scene for what were to become quite devastating experiences later in life. I was the second oldest of four siblings but I grew up thinking I was somehow different to them. I always felt unwanted by my family and this was reflected in me being moved around a lot. Firstly living with the family, then with my Grandad, then back to the family before finally ending up in a children’s home. During all these moves it was only me who went. The rest of my siblings stayed in the family home. I could never get my head around why it was only me being treated in such a way?

Despite a catalogue of neglect and abuse from various people as I grew up there were a few happy memories along the way. I reflect on my childhood quite differently now than I used to. Previously I would always look back and only remember the trauma and abuses that I suffered. Now as I have dealt with some of my demons, I can recall some of the happy times that I had too.

I moved into my Grandad’s at eight years old and spent three happy years there. Grandad was a big strong man with a heart of gold. ‘Hercules’ was his nickname but he was a kind and gentle man. He took me away from the family home where I was being exposed to things that no child should experience. I felt safe with him. I loved the amazing stories that he would tell me, often with me or him as characters within them. It was very soon after moving to my Grandad’s that I began to hear voices. At the time they were pleasant, reassuring voices and as an eight year old I didn’t really worry too much about them. Around that time I also started experiencing a strange feeling that someone was always around me, watching me. That didn’t startle me though, as a child I interpreted it as a guardian angel keeping me safe.

Sadly when I was aged 11, my Grandad became physically unwell and I had to return to the family home in a different town. Here the mistreatment continued, but now I also found myself a target of local bullies. I began to hear more voices, but this time they were more sinister, they would tease me and criticise me in equal measure.

Aged 13, I found myself in a children’s home, I’d started to read about people who hear voices and I’d watched programmes on the television. I came to the conclusion that this was something that I must keep secret. You hear a lot of horror stories from people who spent time in care but for me it wasn’t like that. The staff were very kind and compassionate. One worker really helped me to hone my interest in music. I had taken to playing piano and guitar and she really encouraged me to move forward with this.

Things really came to a head for me much later in life, despite more and more voices appearing, I was getting on with things and doing well for myself. I got married at 18 into what turned out to be a very unhappy marriage, although we went on to have a son together. It was at this point in my mid-twenties that my world fell apart.
I found myself working all the hours I could, I worked freelance as a sound engineer/musician in a recording studio. I was playing in bands on the working men’s club scene at the weekends. I was also in an original band that I wrote all the material for and we were doing very well. We were weeks away from signing a recording contract with a major record label.

Around this time things took a turn for the worse, the voices were now incredibly critical of me and at an intensity like never before. The ‘guardian angel’ feeling of someone watching me was now dark and sinister. I began to be convinced that the police were monitoring my every move and enlisting those around me to help them monitor me. People noticed my unusual behaviour and began asking, ‘are you OK Shaun?’ But this only proved to me that they were watching me closely.

The final incident I recall was during a gig in Germany. I was playing and I noticed someone in the audience staring at me, really staring at me. You can rationalise this and think of course he is staring, he has paid to watch your band…but I had no rational thought left. I thought whatever it is that is happening is going to happen right now, here and now. I left stage mid song, ran from the building and managed to get a flight home leaving all my equipment behind. Very shortly after that I found myself admitted to a psychiatric hospital. It was my first ever contact with psychiatric services and changed my life forever.

My first hospital admission went on to last for three years. For most of that three year period I was sectioned under the Mental Health Act. I arrived in hospital very confused but my overriding emotion was one of fear, I think people struggled to understand this, me being a big six foot four inches man and 18 stone in weight, petrified.

My experiences were translated into meaningless jargon and words such as ‘aetiology’ ‘symptoms’ and ‘prognosis’. I was given a label of ‘paranoid schizophrenia’ but no attention was paid to the circumstances, meaning and context of my life. I received very negative messages about what the future would hold for me, messages like, ‘you will never be able to work again’. One psychiatrist told me that ‘every time I have an episode, it will take a little piece of me away’, what a great future to look forward to for a man in his twenties.

It was against this backdrop of pathologising my distress that I met a man who helped kick-start my recovery, although I probably didn’t realise it at the time. I told a nurse on the ward about some of the abuse that I had endured in childhood and she referred me to see a representative of the male survivors’ network. Some of the first words he said to me were, ‘Shaun, there is nothing wrong with you’. ‘The things you are experiencing are completely normal and understandable in the context of your life and the way you have been treated’. Finally, my distress had been taken away from the domain of ‘illness’ that I wouldn’t recover from. I now had a glimmer of hope that if this is a normal reaction then maybe I can find a way through this.
Despite some of the terrible things that happened during my admission, I met some truly amazing people. I can honestly say hand on heart that I wouldn’t be here to write this now without the support of some of those wonderful workers.

I’ve since gone back to university to firstly study for a degree, then an MSc and I now work as a lecturer in recovery in mental health. I still hear voices all the time but I understand them now. They are incorporated in to my life as part of who I am and that’s the difference now, they are part of me, not the whole of me.

Shaun in conversation with Jerome

Jerome: Reading your story you went through some difficult times with your family, though your grandfather related to you in a completely different way? Do you have any contact with your family these days?
Shaun: My Granddad died several years ago as a very old man but not a day goes by that I don’t think about him with a smile on my face. I don’t have any contact with anyone else in the family other than my sister. I have the odd telephone conversation with her now and again but that’s about it. I suppose growing up apart from my siblings meant we never really bonded so we are not close.

Jerome: Rachel Perkins talks about having something to do, somewhere to live and someone to love as being the key ingredients of mental wellbeing. How does this apply to you?
Shaun: I totally agree, when I think back about my own recovery these were some of the key turning points for me. The first step for me was finding safe housing. Having lived in fear for many years, just knowing I had some where safe to retreat to was life changing. It was from here I had the foundations to begin to rebuild my life. I started on a path through university, then onto voluntary work and then back into paid employment.

I remember having my first paid job after almost 15 years, I had started working six hours a week in a job helping support other service users with their own employment aspirations. After hearing that I had got the job I went to the local pub for a few celebratory drinks with a friend. A friend of his was there and he asked the usual question when faced with a stranger in a social situation, “What do you do for a living?” I replied proudly, “I’m an employment support worker” and a tear ran down my cheek…I felt I was somebody again.

As for somebody to love, through all I have achieved over recent years there has been one person with me through thick and thin. My second wife Sarah, the most amazing women I have ever met. We recently celebrated our 17th Wedding Anniversary and we are still as happy now as we were on that day. Having someone like her around has changed my outlook completely and I count my blessings daily.
Jerome: There is quite a bit of talk about how men do not share their personal problems with others in the way women do? What are your thoughts on this?
Shaun: I think it’s well documented that for many reasons men find it hard to be honest about their problems, not only with others but also with themselves. I’ll be honest and say that it is still something that I struggle with from time to time, but being able to have honest conversations is one of the first steps in dealing with whatever difficulties we find ourselves in.

Jerome: Music used to be very important in your earlier life. What role does it play in your life these days?
Shaun: Music is my big passion, both listening and playing. When I have a bad day I can come home and play my piano and just lose myself. I have realised that stress has a big impact on my wellbeing and I need to manage this. Music gives me that outlet.
When things came to a head for me all those years ago I had lost that stress relief as music was my job too, so coming home and playing didn’t help.

Jerome: What does the concept of hope mean for you?
Shaun: I think hope underpins everything in recovery. People having hope for me has been a key theme for me and ultimately inspired me to have hope for myself. I remember during that three year hospital admission, I was fortunate enough to have the same support worker for the whole time. A great woman who had that uncanny knack of knowing exactly when to put her arm around you but she also knew when you needed a kick up the backside.

I used to walk around staring at the floor unable to make eye contact with anyone. She would say to me, “Shaun in years to come I will bump into you in town with your head held high looking straight ahead”. I didn’t believe her at the time but these days I bump into her quite regularly walking around town with my head held high. Every 1st of December a card from her pops through my letter box and I know Xmas is on its way.

Never ever give up hope, no matter how dark and how bad things become, there is always a way back.

Jerome: What changes would you most like to see in mental health services?
Shaun: The biggest change I would like to see is an end to the over medicalization of peoples experiences. We need to see people who are in distress as people with problems, not people with illnesses. When we strip away the context and meaning from a person’s experiences we can deny them an opportunity to make sense of their difficulties. Recovery is not about the absence of ‘symptoms.’ Attributing problems to ‘diagnosis’ or an ‘illness’ can leave that person sitting in life’s layby waiting for a ‘cure’. I think that’s why so many people get trapped in services.

Jerome: What are your views on the use of medication for mental health problems?
Shaun: I’m not a big fan of medication but it should come down to personal choice. Medication can serve a purpose short term for many people but the huge doses and
lengthy treatment with medication is worrying. I think of medication as sticking
plaster approach, we are just masking the problem. The drivers for the over use of
medication concern me too. From the continuing expansion of ‘disorders’ in the DSM
V (there aren’t many human behaviours left now that are not classed as a disorder),
to the lack of resources within services to offer better options for people who might
be affected by a mental health problem.

Jerome: In your story you say you still hear voices. Is there a role for medication with
people who hear voices?
Shaun: Again, it comes down to personal choice but I think the only way to really
cope with voices is to understand them. I’m a great fan of the work of Romme and
Escher, who promote the need to develop a relationship with voices. Medication can
often leave people with a mental fog, unable to think clearly and work through their
difficulties. Incorporating the experience of hearing voices into my life has been
crucial for me to move forward. Voices are not meaningless symptoms of illness,
they are there to serve a purpose in a person’s life and we need to understand why
they are there.

I can give you an example of a voice that I experience, this one particular voice that
makes me laugh a lot with some hilarious comments (although often at
inappropriate times). Occasionally this voice turns nasty and starts making critical
comments such as “you’re useless, you’re worthless”. In the past it was easy to start
a downward spiral where I would begin to feel bad about myself and the voices
would get even nastier.
Now I recognise that this negative shift happens when I am under stress, what the
voice is trying to tell me is that I’m doing too much work or I’m worrying too much
about something. As soon as I deal with whatever is stressing me at the time, the
voice starts making me laugh again. Their methods might be questionable but their
intent is to protect me.

Jerome: How do you think mental health services can best help promote recovery,
which is said to be the goal of many services?
Shaun: I think services that promote recovery need to practice what they preach.
Just by adding the word ‘recovery’ to a service doesn’t make it recovery orientated. I
am well aware that resources are stretched to breaking point for a lot of services,
but even so changes can be made at all levels. Let’s start with simple things such as
the language we use. Terms such as ‘carer’ for example which can change the
dynamic of how people perceive themselves in a relationship. I remember my wife
refusing a ‘carer’s assessment’ because in her words, she was my wife not my carer.

Another area that is sadly lacking is peer support. I know there are pockets of good
practice around this but all too often peer support is tokenistic. The recovery
movement is built on the shared experiences of those who have experienced and
survived mental health problems but we have peer workers in undefined roles, often
as an add on rather than incorporated into services.
Jerome: Have you been inspired by any mental health or healthcare professionals you have come across?
Shaun: Yes certainly, I have been fortunate to have met several people who went that extra mile to help me overcome my distress and live my life on my terms. I’m not going to name anyone but they know who they are. There are some amazing people who work in mental health services but the ones who have had the biggest impact are those who always believed in me and always spoke to Shaun not to a ‘schizophrenic’.

Jerome: In terms of people with lived experience of mental health problems, have any specific individuals impressed you?
Shaun: I am fortunate enough that during the course of my work I meet many people who have experienced mental health problems. I am always inspired by their stories and the resilience they have shown to overcome adversity. People with mental health problems are often thought about as somehow weak. Contrary to that, I see people who live with mental health problems as some of the strongest people out there, the character of some of the people I meet never fails to amaze me.

All those years ago during my first hospital admission I met Peter Bullimore on the ward, not as a therapist, but as a fellow ‘patient’. We became friends and now all these years later I often work with Peter both nationally and internationally delivering training around hearing voices and paranoia. I love how Peter works with people in such a simplistic way to make sense of peoples distressing experiences. He works like a “sleuth” never missing a clue as to what might be happening behind the chaotic world that people often describe, a true Sherlock Holmes of mental health. Often psychiatry can be so focused on diagnosis, symptoms and treatment that it misses the obvious. Just ask the question, ‘what happened to you?’

Jerome: What challenges lie ahead for you? What do you most want to achieve in the future?
Shaun: In the not too distant future I hope to embark on a PhD around hearing voices groups in a cultural context. My greatest challenge is probably reining in my enthusiasm. My mental health problem stole many years of my life so I have plenty of making up to do.

Jerome: What would you most like to be remembered for?
Shaun: Difficult question, I would like to think that people who find themselves in difficulty could take some hope from my story, mostly though I’d like to be remembered as someone who never did let the bastards grind him down.

Conclusion

Many people with lived experience will find resonance with Shaun’s account. His comment that his mental health problems stole many years of his life, is mirrored in Gordon McManus’ comment of his “lost years” (McManus et al, 2009). Shaun’s recovery journey has benefitted from the love and support of his wife, a number of
the staff who worked with him at his most difficult period, and other inspiring people with lived experience, such as Peter Bullimore. Shaun rightly points to the importance of hope in his narrative and as Patricia Deegan says, “Hope is not just a nice sounding euphemism,” (Deegan, 1996). As Shaun also says, “Never, ever give up hope.”

References


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