Title: Ben Robinson in conversation with Jerome Carson.

Authors: Ben Robinson and Jerome Carson.

Abstract.

Purpose- The purpose of this paper is to provide a profile of Ben Robinson.

Design/methodology/approach- Ben provides a short summary of his life and is then interviewed by Jerome.

Findings- Ben talks about his inpatient treatment for anorexia and his long journey of recovery.

Research limitations/implications- Single case studies provide us with unique insights into the lived experience of people with mental health problems. They often provide us with hints as to how services could be improved.

Practical implications- Ben argues that the voice of service users needs to be heard more by professionals. “The only experts of a mental health problem are the people who have been through a mental health issue themselves.”

Social implications- One of the classic recovery reports talked about “going the extra mile.” Ben talks about how his family therapist would visit him at the end of her working day. As he says, “this was something she didn’t have to do, but wanted to do as she genuinely cared for us.”

Originality/value- Ben is determined to use his experiences for the benefit of others. Even to have helped a single person, will be his biggest life achievement.

Keywords Anorexia, Suicide, Recovery, Hope, Voices, Peer support

Paper type Case study
Introduction.

I came across Ben through a most unusual route. He was recommended to me by my barber, Dean Cocozza! Dean knew of my work at the University and wondered if Ben’s story would be of interest to our students. I arranged to meet Ben and it was clear to me that he had a remarkable story to tell. Indeed his story, like everyone else’s in this series, is not static but continually evolving. Here is his story thus far in his own words...

Brief biography of Ben Robinson

I was 15 when I began to have doubts about my body image. I’d always been a chunky lad, built like a rugby player really. I loved my food, and was always known in school as the ‘human dustbin’. I had never been called fat, and had actually always been a sporty person from a young age. I loved playing tennis and golf, and spent any spare time participating in those sports. My mates were all slim and good looking, and gradually for the first time in my life, I started to think that I wanted to be like them. So I decided to change my approach to my diet and started to eat ‘healthy’. At the time, this was just simply swapping chocolate and sweets for bananas and fruits. I also decided to join the gym with a view to becoming ‘leaner’ and to ‘build muscle’.

However, knowing what I know now, this is virtually impossible to achieve. I didn’t seek any professional advice regarding the gym. I went in, pumped weights and came out. I hated my chest and arms, so that’s all I trained. Ego lifting! When I returned to school in 2010, after the summer break, lots of people commented on how much better I looked for losing a bit of weight. Comments like this would obviously boost your confidence, which motivated me even more. I initially felt better for it too, and clearly other people had noticed.

So this became my motivation to lose more weight. The exercise increased. I was going to the gym twice daily, and cutting my meals right down. The weight soon began to drop off and suddenly it had turned into an obsession. I decided to cut fat out completely from my diet as I thought that this would help me lose body fat. I gave up weight training, and started to swim. But nothing was ever enough to stay happy. After six months of this, I was doing 150 lengths a day, and I ate one yoghurt a day. My initial thoughts of trying to look like my friends had driven me to radically change my lifestyle. I wasn’t true to myself.

I then developed a voice in my head. It told me that I was fat, every minute of every day. Clearly I wasn’t. Everybody could see that. Yet I believed and trusted that voice, rather than the network of friends and family around me. My weight fell to 50kg and
positive comments about my weight loss soon stopped. People were now saying I’d
gone too far, and to stop dieting, but it was too late. The comments made me feel
even lower, you begin to feel unattractive, unloved and the negative comments saying
‘you’re too skinny’ didn’t help at all.

The voice in my head had become my new friend. I didn’t believe anything anybody
else said, and I now only believed the voice. A few more months went by and I had
totally stopped eating. My energy levels were rock bottom, and I was finding it hard
to even find the energy to get dressed. Some days, I felt so weak, that I would stay in
bed and pretend I was ill.

This led to my admission to hospital and I was put on a re-feeding programme. My
weight was 41.7kg, and my body was in starvation mode. It had fed on all my body fat
and muscle, and my organs started to become affected. On the first night of my
admission, my mum and dad were warned that I might not make it through the night
because my body was so weak. The doctors were nearly right, every time I went to
sleep my heart rate slowed, and I had to be continuously monitored. Thanks to the
medical staff, I made it through that first night, and anyone would think that this
would be enough to make me realise the importance of needing to eat. However, if
you understood anorexia, you’d know that nothing is ever a ‘wake-up call’.

The medical team decided the only way they could start to control my diet, was to
feed me through a nose tube. As much as I didn’t want the tube to be fitted, I had no
choice. I stayed in hospital for six weeks before a decision was made to transfer me to
an inpatient unit for a year, whilst being sectioned under the Mental Health Act.

During my time in the inpatient unit, things got worse. They were forcing me to eat,
stopped my exercise, and took control. This made the illness become more impulsive,
to a point where I couldn’t cope with it any more. At this point I didn’t want to get
better, and I felt worthless. One day I asked myself ‘what is the point of my life carrying
on anymore?’ I took a turn for the worse, and I decided to try and hang myself. Luckily,
I was found by the staff and rescued from the situation. Initially this made me feel
even worse, and I continued to have suicidal thoughts, and I would take any
opportunity to hurt myself or try to kill myself. The illness was now winning.

After the last suicide attempt, something “clicked” in me. I decided that I wanted my
life to get better, because at this point it couldn’t get any worse. I was scared to take
my first steps forward towards recovery, not because I didn’t want to, but because I
knew how the illness would make me feel. Anorexia makes you feel horrible regardless
of whether you’ve eaten or not, so I decided to bite the bullet and take my first steps
forward, and it worked. Obviously, that first step was very hard to do, and I had days
where I gave into the illness. The road to recovery from anorexia is not easy, you have
to realise that you will have setbacks, but a setback is not a failure. A set back is a
learning curve.
While I was in the inpatient unit, I gradually gained weight, and for any anorexic this is their worst nightmare, because it goes against what the illness wants. The word weight gain meant ‘fat’, and every time I was told I had put on weight, I cried. Even though I knew that it was the only way for me to get my life back, my mind couldn’t rationalize the positives of weight gain. Eventually, after months of fighting I achieved a healthy weight. I felt fat, but I didn’t start to restrict my diet because of the weight gain. I continued to eat my meals, and cope with the impulsive thoughts from the voice in my head. When you get to a healthy weight, your brain starts to be able to function properly again, due to it being properly nourished, and I had more strength to deal with the bad thoughts from the anorexia. I can say “hand on heart” that when you get to a healthy weight, you will feel so much better mentally. BUT just because you’re a healthy weight, this does not mean that you’re fat. Don’t listen to the anorexia, it is just lying to you!

When I was discharged from the unit, this was probably the scariest time of my journey, because I would no longer have that 24/7 care that I’d had for the last year. Initially, after a few weeks of being out of the unit, the illness took control again and I relapsed, and I had lost all the weight I had gained whilst in hospital. BUT….. something stopped me from letting it go too far. I now had the strength to recognize that enough is enough, and fought back against the anorexia. I gradually gained the weight back that I had lost, and from this point on, I went from strength to strength. I got a full time job, whilst battling my illness, which was still very strong, despite being a ‘healthy weight’. The job distracted me from my illness and kept me busy, which meant I didn’t have time to think about the food I had just eaten. As the years went along, I decided that I wanted a career change. Any change in routine whilst you have anorexia is daunting, but at some point in your life, you will have to step outside of your comfort zone. I went into the field of healthcare, into a job that I was once on the receiving end of. The only experts of a mental health problem are the people who have been through a mental health issue themselves. I am now a support worker supporting people going through similar problems that I once went through.

Life is now good. I have a job I love, and I have my own business, which delivers training for professionals who support people suffering from mental health problems. The main thing is, I AM HAPPY. Happiness is a feeling, which two years ago, I thought I’d never have again. I still have my bad days, but I don’t listen to the voice. I am able to control the voice, but it’s taken a lot of time, a lot of steps backwards but double the steps forward.

The key to recovery is to believe. Believe that you can get better. Believe that you are worthy of a good life. Believe that you are loved.
Ben in conversation with Jerome

Jerome: Anorexia in men is much less common than in women. Do you think it is understood as well?
Ben: No, not at all. In today’s society, men are perceived to be the sex who are unbreakable and cannot be seen as ‘weak’. We only see the stories of female sufferers’ success stories on social media and in the news, but it’s never men. I believe anorexia is just as common in males as it is in females, but this isn’t known, due to not man men having ‘come out’ and spoken about their eating disorders. Not as much research is conducted on men with anorexia. I think it’s also the ‘shame’ that men feel, when they have to admit they have a problem, especially an eating disorder. When I was diagnosed, everybody used to say ‘what? You’ve got anorexia? You’re a man!’ This made me feel even more isolated than I already was, because I thought nobody understands. This is why I do the work I do, to raise awareness for eating disorders in men.

Jerome: You made a number of suicide attempts while you were an inpatient. You said that after the last one something “clicked” and you wanted to get better. How do you reflect on this now?
Ben: I can’t explain what or how it “clicked,” but it just did. It wasn’t that I woke up one morning and thought ‘I want to get better now’. On the last attempt, a certain staff member was very blunt to me and actually said that ‘This is the coward’s way out’. People may think that this was a very harsh comment, but for me it worked. It made me realise that I was giving up to easily, and as long as I could remember, I had by nature always been a fighter and never liked losing. So I used this mind frame going forward. As much as I wanted to give up, I also wanted my old life back just as much. But if it wasn’t for that particular comment (tough love) from that staff member, then maybe something wouldn’t have clicked. So I thank him for basically saving my life.

Jerome: You now work with people who are going through similar problems that you did. How do they respond to your own remarkable story?
Ben: I think the fact that there is hope, and I can show this using my own story, often helps. I have spoken to sufferers at rock bottom, who believe that life can’t get any better, and by me showing them that I have been in that exact place once, and then showing them where I am now, spurs them on. They see that I have felt exactly like them and thought what they are now thinking, but yet I am at the place I am today, and it proves to them that the illness is telling them lies that things can never get better. At the end of the day, it’s about giving them hope and proving to them that recovery is achievable.

Jerome: What changes would you most like to see in mental health services?
Ben: I think that funding has got to be the big change I would like to see. We have people on waiting lists for 12 months for an assessment. People attempting to commit
suicide and then attending A&E, only to be sent home on the same night. All of these people all need one thing and that is HELP. The problem is that there aren’t enough resources out there to give these people the help they need. The other change I would like to see, is people being educated in workplaces, schools, colleges, universities etc, about mental health. The problem with someone suffering from a mental health problem, is that you can’t see what is going on inside their head. So how can you help? Well if you had a little bit of knowledge about mental health problems, you’d maybe be able to see the behaviours, which would highlight what is wrong with them. By educating people of all ages about mental health problems, this would help reduce the stigma in today’s society surrounding mental health.

Jerome: What are your views on the use of medication for mental health problems?
Ben: When I was admitted to an inpatient unit, the first thing they did was put me on anti-depressants and anti-psychotics. At first, my family and myself were adamant that I didn’t need the medication. I couldn’t see myself as someone who takes ‘anti-depressants’ or somebody who was ‘psychotic’. But when I started taking them, it alleviated the problems so much. It reduced my anxieties around mealtimes and around food itself, and it started to make me think more rationally. There are a lot of people who believe that medication shouldn’t be used as the first line of treatment in mental health problems, which I agree with to a certain extent. However, in many cases, like my own, some people are in such a bad state of mind that they aren’t ready for therapy. So why not take a tablet to help alleviate their issues or at least take the edge off them. There is a stigma around taking medication for mental health problems. But I don’t see what the issue is? Diabetics take insulin to help with their illness, just as cancer patients have chemotherapy to help with their treatment. It’s all the same, but yet again, there is this stigma linked to mental health.

Jerome: How do you think mental health services can best help promote recovery, which is said to be the goal of many services?
Ben: I think mental health services need a lot more ex-service user input, to show the people in services that there is hope and that recovery is possible, which I think will help a lot more people instead of doing care plans with their case managers/therapists etc. I also think that there needs to be more funding in the mental health services, so that patients/service users, can be seen on a more regular basis. For example in my case, I went from one year’s worth of 24/7 care, to a one hour a week CAMHS appointment. It didn’t work. I relapsed within 2 months. I think depending on each individual’s stage in their recovery, they need to be given a more intense plan, to help them through the niggly parts along the way. You can’t just expect an anorexic to meet a dietician, who then increases their meal plan and expect the sufferer and the family to do the work for the next week. An increase in a meal plan is very distressing for a person suffering from anorexia. Yet sometimes services expect that person to cope with these thoughts and feelings for the next week on their own? They are in that service for a reason and that is for specialist help whilst they are suffering. I think that there needs to be more training for medical staff who work with mental health patients, but from an ex-service user perspective. It’s okay going through university
and reading books on mental health etc., but the only experts are the people who have been through it themselves. So why not use the experiences of people who have suffered with mental health problems, and put them to good use? I think it would give the medical professionals a much better understanding of each individual mental health problem and show how people really feel when they are suffering from a mental health issue.

Jerome: Have you been inspired by any mental health or healthcare professionals you have come across?
Ben: I definitely think that if it wasn’t for what the staff did in the inpatient unit I was in when I was 16, then I wouldn’t have been where I am today, or maybe even be here at all! Their work helped me realise that anorexia wasn’t my friend, but was my enemy. A family therapist who used to work with my family and I, never lost faith in me, even at the times I was at my lowest. She always use to tell me that she believed in me and that she wasn’t ‘going to let the anorexia win’. This helped me massively because I felt like I wasn’t fighting the illness on my own. That particular therapist always use to stay past her finish time at night, and come onto the unit and see me before she went home. This was something she didn’t have to do, but wanted to do as she genuinely cared for us. That particular family therapist and some of the support staff, genuinely saved my life, and I will never be able to thank them enough for that.

Jerome: In terms of people with lived experience of mental health problems, have any specific individuals impressed you?
Ben: I think anybody who goes through a mental health illness deserves credit and all these people deserve to be recognised as being strong human beings. To go through a mental health problem isn’t easy, and I think you have to have so much strength to be able to even cope with a mental health problem, never mind recover from one. No specific people have impressed me but I think the amount of mental health awareness that is being raised at the moment not just by celebrities, but by everyday people who are speaking about their own issues, is something that really needs to be captured and looked at as a success. These are the things the government and NHS services need to look at to see what works, so that they can implement these ideas into public services.

Jerome: What challenges lie ahead for you? What do you most want to achieve in the future?
Ben: I want to continue to work with people going through what I went through, to help them get their own lives back on track. At the moment I am in the process of writing a book for professionals to help them in their own line of work, so getting that up and running is the next challenge. Then I have other ideas that I would like to explore and hopefully see implemented, such as providing some training to the “blue light services,” who deal with mental health related incidents each day, to ensure that people involved in the “blue light services” get the help they need. Overall, though I just want to continue as I am doing and carry on pushing the illness to the back of my mind each day to the point where I beat it completely.

Jerome: What would you most like to be remembered for?
Ben: This is a tough one, but for me, through the work I do, if I can turn around in 20 years’ time and just one person out of the hundreds I’ve spoken to/helped, and they say ‘Ben you helped me recover’, that would be the biggest achievement for me, because then I know that I have actually helped turn someone else’s life around from bad to good. There’s no better feeling than that.

Conclusions.
Ben’s story is a remarkable story of his battle against anorexia, which led him to attempt suicide. After spending a year as an inpatient, he began the long struggle to transform his own life. In later becoming a support worker he was able to use his own experiences to help others. He is determined to contribute more to improving the understanding of mental health problems amongst professionals, ranging from medical staff to paramedics. He is going to join a line of inspiring individuals who have gone before him, to help others to appreciate the reality of suffering with a severe mental health problem, in the hope that this not only reduces stigma, but also understanding.

About the authors
Ben Robinson works as a peer support worker and also has his own consultancy business.

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