Remarkable lives: Jo Mullen in conversation with Jerome Carson.

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Title: Jo Mullen in conversation with Jerome Carson.

Authors: Jo Mullen and Jerome Carson.

Abstract

Purpose – The purpose of this paper is to provide a profile of Jo Mullen.

Design/methodology/approach – Jo provides a short background to her life and is then interviewed by Jerome.

Findings – Jo tells us about the teaching resources that she has developed to increase understanding of Borderline Personality Disorder (BPD).

Research limitations/implications – While this is a single case study, it contains numerous helpful insights of how Jo has developed and presented her work, along with two mental health nurses, and of the high quality educational interventions she has produced.

Practical implications – Jo presents a model of co-production, where service partner and mental health professional are equals.

Social implications – It would be helpful if mental health services invested in supporting talented individuals like Jo, to develop and disseminate the tools she has created.

Originality/value – Thus far Jo has written her own personal account of what it is like to cope with BPD, a bigger training resource, “Wot R U Like?” and a board game, Personapoly, to help individuals solve social and personal problems.

Keywords Borderline Personality Disorder (BPD) Mental health nurses Service partner Co-production Person centred care Education
Introduction

I came into contact with Jo by an unusual route. Jo had e-mailed me about the possibility of studying for a PhD by Professional Practice, via distance learning. Through a series of e-mails I got to know Jo’s story and came to learn of her innovative work. We learned we had a mutual clinical psychology acquaintance and also that we had a connection with the Scottish town of Elgin, where Jo now lives. Here is Jo’s remarkable story in her own words [...] .

Brief biography of Jo Mullen

At 47 years old, I feel that I’ve lived a very long life. I managed to survive a childhood full of anxiety and too much time spent away from my mother. Entrusting several others with my care, she expected them to show kindness and ensure my safety. Some of them however, couldn’t deliver on either. Teenage years brought difficulty relating to others amidst desperate attempts to fit in and a futile search for someone to look after me. My twenties and thirties saw much of the same. At 33, I received a diagnosis of Borderline Personality Disorder (BPD) during my first admission to a psychiatric ward. It was from this point on that my life started to make more sense. Up till then I had labelled myself in wholly negative terms because of the feelings, thoughts and behaviours I couldn’t control. Also, I reasoned, that if there was an official name for the difficulties I was experiencing, then surely there must be others in the world just like me – perhaps I didn’t need to feel lonely or strange anymore. I felt relieved. I truly believe, however, that had I received the diagnosis much earlier in my life, I wouldn’t have managed to push myself through O-Levels, A-Levels, a degree and then go on to become a teacher. Ignorance wasn’t exactly bliss, but it did allow me to fulfil my parents’ high expectations and gain a good education.

Following the diagnosis, I enthusiastically embraced having BPD as an identity. It wasn’t as unhealthy as it sounds though because it led to a shift in the way I related to my community mental health nurse, Lisa Shaw (formerly Edwards). We were in this together, both learning what it meant to live with something now officially considered to be “no longer a diagnosis of exclusion,” (NIMHE, 2003). In 2005, in order to help me to move forward, I set up a local support group for people like me with a diagnosis of BPD, and asked Lisa to join, but not to lead it. Meeting weekly as equals, we would set individual goals, and each of us would give and receive support. Then, after the group had been going for a few months, I approached the Chair of the Scottish Personality Disorder Network (SPDN) to ask if she would be interested in hearing about the way service users and professionals were collaborating. The result was that, as a group, we delivered presentations and workshops at SPDN conferences over a two year period, and travelled around Scotland, helping other service users and nurses to set up their own collaborative support groups. In 2007, Lisa and I won an award from the Scottish Mental Health Nursing Forum for our innovative approach to providing a
community service. Also in this year, I finally finished my MA in Education (through the Open University), of which I am extremely proud.

By 2009, I was equipped with a good amount of confidence so I made the decision to go back to teaching - it was a disaster! My anxiety got worse, I continued to experience difficulty relating to others and my self-esteem plummeted. Ever the workaholic and perfectionist, I felt like a complete failure – again. The next few years saw more emotional and mental instability and a suicide attempt. I therefore made a request for another community nurse. I specifically asked for Nadine MacArthur, the person who had been my named nurse during my first hospital admission a decade before. So, from the autumn of 2013, the next phase of my life began. At first, I needed a lot of support from Nadine because I was really struggling. However, something happened in early 2014 that provided me with the hope that I could feel better about myself again. Aware of the collaborative work that I had done with Lisa, Nadine asked for my advice about helping a patient recently diagnosed with BPD as there were no resources locally. Creating learning materials to meet children’s needs was what I had enjoyed most about teaching so I welcomed this opportunity. With Nadine’s support, I wrote a booklet called ‘Borderline Personality Disorder A Personal Story.’ I wanted to describe some of the difficulties I faced as a result of living with BPD, but also give examples of the strategies I use to help me cope. The booklet was warmly received by Nadine’s team and they placed an initial order for 150 copies. Then, towards the end of the year, I read out my booklet to delegates at the SPDN conference in Glasgow. The feedback was lovely, and sales and orders came to more than 250 – I was blown away!

‘Borderline Personality Disorder A Personal Story,’ was actually the introduction to a much bigger resource that I had been working on - a programme called, Wot R U Like? designed to help people develop self-awareness. Each of the sections: ‘Feelings, Thoughts, Behaviours;’ ‘Relating to Others;’ Identity;’ and ‘Planning for the Future,’ are all pertinent to those with a BPD diagnosis. The programme consists of around 35 activities, several of which are interactive, and can be delivered by a range of mental health professionals. It can be used as a stand-alone or as a resource to prepare people for (group) therapy. Wot R U Like? had its first public airing in 2015 at the three day British and Irish Group for the Study of Personality Disorder (BIGSPD) conference in Leeds, where I presented it as a poster. This was the first conference that I had attended on my own, and due to my anxiety, I didn’t feel able to go to any of the sessions. I did, however, make several important connections with people, sold a few copies of the programme to services in England dedicated to helping people with a diagnosis of personality disorder (including the therapeutic community at HMP Gartree), and won the prize for best poster. Since then, Nadine and I have presented at several conferences together and delivered Wot R U Like? training sessions to mental health professionals and student nurses in Elgin, Aberdeen, Inverness, Dundee and Fife.
2017 was a pivotal year for us – as a result of delivering a workshop at the BIGSPD conference in March, *Wot R U Like?* has been purchased by the Peaks Unit at Rampton High Secure Hospital, and it will be trialled in acute psychological services across three counties in Wales. In addition, immediately after the conference, I had my next big idea: a board game for people with a BPD diagnosis. I used to hate playing a certain well-known board game as a child, resulting in many tantrums and accusations of personal attacks when other players charged me rent for landing on their properties! *Personapoly* then, is a game without a competitive element. Players collect Activities and Qualities as they move around the board. Everyone practises the skills of Active Listening and Giving Opinions, and works together to solve challenging personal and social problems. I also created a Youth Version to help teenagers to build resilience.

Feeling the need to show my appreciation for the level and nature of support that I had received from Nadine, I nominated her for the Royal College of Nursing Patients’ Choice Award. She was selected as one of five finalists and attended the Awards Ceremony in London in May. Then, towards the end of the year, Nadine and I decided that I no longer needed her to be my nurse. However, at the same time, Nadine expressed her wish to continue our work together, presenting at conferences, delivering training sessions and promoting the resources. I felt so grateful, realising that I must be OK as a person if she wanted to continue our working relationship.

This year, will hopefully be just as exciting. Nadine and I will be presenting, *From Therapeutic Relationship to Working Partnership – A Journey Towards Independence*, as a poster and a twenty minute talk at the NHS Grampian Celebrating Excellence Conference. Then I will be presenting *Personapoly* as a poster at the BIGSPD conference in Cardiff.

Finally, if I can balance my strengths and limitations, I hope to pursue a PhD by Professional Practice, mainly by distance learning, through the University of Bolton. Referring to the work I’ve done over the past decade or so (and the context in which this has been achieved), I’ll be calling my dissertation, *From PD to PhD: An Auto-ethnography*, and will be exploring the many identities I have assumed over this period of time.

Jo in conversation with Jerome

Jerome: Jo you mentioned embracing the concept of Borderline Personality Disorder (BPD). For many years many mental health staff had incredibly negative attitudes towards BPD. Do you sense attitudes are changing?
Jo: Personally, I’ve been treated with a great deal of kindness and respect by the vast majority of mental health staff with whom I’ve had contact over the past fifteen years. There is really only one person who stands out as having had a negative attitude towards me, but in the light of the way in which she also treated other patients, I feel certain that her apparent dislike of me had nothing to do with my BPD diagnosis.

Although my experience has been overwhelmingly positive, I am very aware that for others with the diagnosis, this is not the case. There are groups of service users and professionals that have been working very hard over the years, to challenge the negative attitudes and stigma that a BPD diagnosis sometimes attracts. The Knowledge and Understanding Framework (KUF), for example, is a co-produced personality disorder awareness programme that has been delivered to many mental health staff in England. In our own small way, Nadine and I seek to do something similar locally. A training session we delivered for nursing staff in Fife, for instance, was part of a research study led by the University of Abertay to ascertain whether such an intervention could successfully challenge negative attitudes. Other training sessions that Nadine and I have delivered have been for mental health nursing students. They have resulted in positive feedback, leaving us feeling very hopeful for the future.

Jerome: While you say that you did not feel you could work as a teacher, this has not stopped you acquiring an MA in Education and developing teaching materials that might help services and individuals struggling with BPD. How do you see your future roles developing?

Jo: To be honest, I’m open to anything, and fortunately I’m blessed with a constant flow of ideas for new projects. Fundamentally, I still see myself as a teacher and, with this in mind I’d like to develop Wot R U Like? further. So I plan to create an on-line course for people like myself who find it challenging to leave the house to access support. I’d also like to expand the BPD awareness training, in partnership with Nadine, delivering to a wider audience including GPs and those health professionals whose remit is to treat physical conditions. I co-delivered a session on self-harm and BPD to general nursing staff from the A and E department of my local hospital, and it was very well received. In light of this type of work, I see myself as more of a ‘service partner’ than a ‘service user.’

Jerome: You talk about writing a PhD entitled “From PD to PhD: An auto-ethnography.” You have written a booklet on your personal story. Have you thought about writing a book?

Jo: Several years ago I had an idea for a book but I’m not sure it will ever come to anything. It’s a series of vignettes called Chairs which describe significant experiences in my life that occurred while I was sitting down. I do feel that, because my ideas come thick and fast, I’m
best suited to projects that can be broken down into chunks and don’t take me too long to complete. For example, nearly twenty years during my transition from London to Scotland, I wrote several short stories which I have since put together as another booklet entitled, *Rescuing the Children: A Collection of Therapeutic Stories for Adults.*

Perhaps I could turn my PhD thesis into a book?

Jerome: Stephen Fry helped change attitudes toward bipolar disorder. Do you think something similar is needed for BPD?

Jo: Although not classed as celebrities in the popular sense, there are already many people working tirelessly within the field of Personality Disorder (both those with lived experience and mental health professionals), to help bring about a better understanding of the difficulties faced by people like me, and also to shed light on the kind of childhood experiences that often lead to a diagnosis of BPD. Two recent publications that take this on board are the *Consensus Statement on Personality Disorder,* (co-led by the MP Norman Lamb, and Sue Sibbald, a Peer Specialist, MIND, 2017), and the *Power Threat Meaning Framework,* (by Dr Lucy Johnstone and other colleagues, British Psychological Society, 2018).

I don’t honestly think that having an advocate like Stephen Fry would be of any benefit given the on-going debate around the validity of the BPD diagnosis itself. I often wonder though, whether a certain member of the royal family, had she not died prematurely, may have taken up such a position...

Jerome: What does the concept of hope mean for you?

Jo: Well, I spent the first half of my life ‘living in hope’ that things would get better, but they didn’t, until I met Nanette, a ‘teacher’ in the broadest sense, who told me that I had a choice about what happened in my life. This was a totally new concept for me but so powerful. Since then, I have endeavoured to make statements of intention regarding the kind of experiences I want to have rather than hoping that certain things will happen. Even though I don’t tend to use the concept of hope now, I do recognise that it was essential for the people who provided me with care and support, to include it in their own repertoire of resources, particularly at times when I was experiencing extreme emotional distress. They held a vision for me that my life would improve, even if in those difficult moments, I was not capable of sharing that vision.

Jerome: What changes would you most like to see in mental health services?
Jo: I firmly believe that most people who choose to work in mental health services do so because they care and genuinely want to help. I would therefore like to see frontline staff recognised and appreciated even more for the positive contribution that many of them make. At the same time, however, there are service users who have not been treated well by those delivering services, and it is right that their voices are also heard. So, for me, there has to be a coming together, a move towards a greater understanding of each other as human beings – outside of the stereotypes and boundaries that society (especially psychiatry) has imposed on all of us. When I was teaching, for example, I was constantly learning about the children and about myself, making a conscious effort to consider the strengths and experiences that they, as well as I, brought to the learning environment – something that was talked about but not often seen in practice all those years ago. I think the approach adopted by me, Lisa and Nadine could be an option for some people providing and using mental health services. For opportunities to arise, however, the concept of co-production of services and resources needs to be offered as one of many routes to a greater sense of well-being and needs to be embedded in policy at the highest level, accompanied by the will to implement it. I’ve been fortunate enough to have experienced the many benefits of this way of working with both Lisa and Nadine, who did indeed have the will.

Jerome: What are your views on the use of medication for mental health problems?

Jo: A highly contentious issue... I’ve been taking medication myself for fifteen years but have recently decided to take a closer look at the evidence, so my answer for the moment has to be, ‘The jury is out!’

Jerome: How do you think mental health services can best help promote recovery, which is said to be the goal of many services?

Jo: There is much debate around the use of the term ‘recovery.’ Personally, I find it difficult to move past the common understanding of the word which points to some sort of return to a healthier state – as I don’t remember ever having had one in the first place, such a challenge would be beyond me! I also fear that it’s (another) ‘one size fits all’ strategy that has the potential to lose sight of individual experience, so instead I would opt to advocate the use of just one of the principles from the recovery model as an overriding goal for mental health services – the pursuit of person-centred care. Having this as the main aim would allow staff and those they seek to support, to use aspects of the recovery model some of the time, with varying emphasis, or none of the time, according to an individual’s needs and wishes. So I suppose what I’m saying is, any model (including recovery) needs to be flexible, to firstly incorporate the unique personalities, strengths and experiences of both
service users and providers, to take into account the infinite nuances within the relationships between them, and crucially, to consider a person’s readiness for change.

Jerome: Have you been inspired by any mental health or healthcare professionals you have come across?

Jo: My answer is, ‘just about everyone who has ever supported me,’ because I’m in awe of people who can listen and respond with genuine kindness to some very difficult stories and experiences and not lose their own sense of self as a result. This is something that I personally find extremely hard to do.

I’ve already talked about the contributions made by Lisa and Nadine but I’d like to mention my psychiatrist, Dr Ann Hodges, as well. She’s another person who has given me a lot of encouragement over the past few years with regards to my projects and plans, always looking out for opportunities that I might be able to tap into. Besides this, I have much respect for Ann because she exercises caution with regard to any requests from me to increase my medication when life is particularly difficult, and has at several points, asked me to consider reducing or stopping some of it. I also admire her attitude towards the diagnosis of personality disorder – Ann prefers to think of people as experiencing a ‘constellation of difficulties,’ to reflect how much many of us struggle, and as a way of avoiding a label that can be stigmatising.

Another person who I think is amazing is Suzanne, a clinical psychologist. She helped me to talk about some very painful experiences, and my trust developed to such an extent that at one point, I felt able to show her several sheets of paper on which I’d written down everything I’d ever felt guilty about, and you know what? She didn’t judge me or treat me differently as a result. In fact, when she told me she was leaving the service, and would return to the area only occasionally, I asked if she would continue to see me as a private patient because I felt that I was making real progress. Not only did she agree to that, but she said she would offer her help without payment. I was overwhelmed by her generosity, and so very grateful.

Finally, there are two other people who have helped me a great deal over the past few years. The first is Sharon (Ann’s secretary), and the other is Gwen, the healthcare assistant at my GP practice who does my blood tests. Neither has trained in mental health or has letters after her name, but both are incredibly good at listening to me with compassion and empathy when I’m struggling. For me, these two have been the unsung heroes on my journey, and as such, deserve recognition.

All of these wonderful people work in Moray, a county within NHS Grampian in the North East of Scotland.
Jerome: In terms of people with lived experience of mental health problems, have any specific individuals impressed you?

Jo: Yes, many of my closest friends who, like me, battle daily with their own personal problems, and without whose continued support and friendship, my life would be much more challenging and not as enjoyable. There is one other person though, and that’s a woman who holds down a full-time job at the place where I take my posters and booklets to be printed. Like me, she received excellent training in graphic design and desktop publishing as part of a project run locally for people experiencing problems with their mental health. Also like me, she struggles with anxiety but a couple of months ago she managed to fulfil her dream of getting married on her favourite Scottish beach.

Jerome: What challenges lie ahead for you? What do you most want to achieve in the future?

Jo: Although I feel that I’ve developed a lot of self-awareness and a range of (healthier) coping strategies, I expect that some aspects of life will always feel difficult or uncomfortable, but who knows? It is, however, my physical health conditions that are likely to pose more of a threat to my future. Two years ago I was diagnosed with type 2 diabetes and psoriatic arthritis. The arthritis in particular is already having an impact on me. I sometimes struggle to write or use a computer because of the pain and reduced movement in most of my fingers. I’m planning ahead though, having secured a kind offer from Nadine to help with the typing of my PhD dissertation if I can’t manage.

With regard to future achievements then, it has to be a case of ‘wait and see,’ although I’m already considering different ways of creating resources, for example producing videos instead of printed materials, and focusing more on public speaking. However, I would definitely miss the graphic design element of my work. I do have one big work-related ambition that I’d like to achieve at some point in the future, but it’s something that I don’t feel ready to share with anyone just yet! Aside from that, I’d like to have more times where I don’t feel anxious so that I can leave my house and walk my dog whenever I want.

Jerome: What would you most like to be remembered for?

Jo: I’d like people to remember that I never passed up an opportunity to learn, to create or to crack a joke, that I successfully healed my relationship with my mother, and that I was grateful for all of these.
Conclusions

Attitudes towards Borderline Personality Disorder have changed over recent years, from “no longer being a diagnosis of exclusion,” (NIMHE, 2003) to the pioneering therapeutic work of Professor Marsha Linehan (Linehan, 2015). This paper has shown how one remarkable individual, supported by professionals and friends, has developed innovative educational and training materials for both people with BPD and those who work with them. Jo Mullen hopes to embark on a PhD by Professional Practice and to make the journey from PD to PhD. She ends her amazing account by saying she would like to be remembered for never passing up an opportunity to learn and to create and crack a joke. In this she reminded me of Abraham Lincoln, who stated, “…that I always plucked a thistle and planted a flower where I thought a flower would grow,” (Burlinghame, 1997). Personally, I am convinced that Jo will plant many flowers, which will help many people diagnosed with BPD.

References


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