

OVERCOMING THE TYRANNY OF LOW EXPECTATIONS, DIAGNOSIS, AND VICTIMHOOD

Superando a tirania de baixas expectativas, diagnóstico e vitimização

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ABSTRACT: My mental health issues began with childhood sexual abuse and the physical and emotional ramifications of this. My teen and adult years were mapped by periods of suicidality, depression, anxiety and self-medication with alcohol and marijuana. Distressing voices and images plagued my waking hours and regular sleep evaded me. I was diagnosed with Bipolar Schizoaffective Disorder and informed by a psychiatrist: “You will never work and never be a valuable member of society”. This prognosis and diagnosis caused a worsening of depression and shame. However, I accepted it as fact and saw myself as a victim of my abusers, my diagnosis, enforced treatment and my prognosis. A psychiatric diagnosis coupled with victimhood and the tyranny of low expectations often marginalises and alienates people from society and from reaching their full potential. At the age of 40, a peer worker compassionately challenged me to shake off the imposed low expectations of psychiatrists, family, community and myself. Although I had never previously held permanent employment, within a short time, I became a peer worker. Over the course of my lived experience career, I have held executive positions including being the Director of Consumer and Carer Affairs in a public mental health service, Deputy Commissioner with a state Mental Health Commission, founder of a training and consultancy business and General Manager of Inclusion for a large mental health community managed organisation. People with lived experience deserve to meet their full potential and be contributing members of society and their families.

keywords: Lived Experience. Workforce. Peer Support. Diagnosis. Citizenship.

RESUMO: Meus problemas de saúde mental começaram com abuso sexual na infância e as ramificações físicas e emocionais decorrentes. Minha adolescência e idade adulta foram mapeadas por períodos de suicídio, depressão, ansiedade e automedicação com álcool e maconha. Vozes e imagens angustiantes atormentaram minhas horas de sono causando insônia.

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Fui diagnosticado com Transtorno Esquizoafetivo Bipolar e informado por um psiquiatra: “Você nunca vai trabalhar e nunca será um membro importante na sociedade”. Esse prognóstico e diagnóstico agravou a depressão e a vergonha. No entanto, eu aceitei isso como um fato e me vi como uma vítima de meus abusadores, meu diagnóstico, tratamento forçado e meu prognóstico. Um diagnóstico psiquiátrico juntamente com a vitimização e a tirania de baixas expectativas muitas vezes marginaliza e afasta as pessoas da sociedade e do potencial alcance de plenitude. Aos 40 anos, um colega de trabalho me desafiou respeitosamente a me livrar das baixas expectativas impostas por psiquiatras, família, comunidade e eu mesmo. Em pouco tempo me tornei um suporte de pares senter tido um emprego anteriormente. Ao longo da minha carreira de suporte de pares, ocupei cargos executivos, incluindo o de diretor de assuntos do consumidor e cuidados em um serviço público de saúde mental, comissário adjunto de uma comissão de saúde mental estadual, fundador de uma empresa de treinamento e consultoria e gerente geral de Inclusão para uma grande organização de saúde mental gerenciada pela comunidade. Pessoas com experiência vivida merecem atingir todo o seu potencial e ser membros reconhecidos pela sociedade e familiares.

Palavras-Chave: Experiência Vivida. Trabalho. Suporte de Pares. Diagnóstico. Cidadania

1 INTRODUCTION

Like most people with lived experience, my mental health issues began with trauma. For me, it was childhood sexual abuse and the physical and emotional trauma these inhumane acts inflict long after the abuse has finally stopped. My teen and adult years were mapped by periods of suicidality, depression, anxiety and self-medication with alcohol and marijuana. Distressing voices, images and thoughts of suicide plagued my waking hours and peaceful sleep has evaded me into my adult life.

I married young because I was in love, but also because my husband gave me safety. I gave birth to two beautiful daughters. However, I lost my baby son at birth and had three miscarriages. I still think about my baby every day. I like to imagine my son with my beautiful brother who had the same diagnosis as me, and died young. I have been blessed with two wonderful grandsons. I also inherited four daughters after my close friend died of breast cancer.

I was diagnosed with Bipolar Schizoaffective Disorder at the age of 37. In delivering the diagnosis the psychiatrist informed me that “*You will forever be impacted by it and the best you can hope for is rigid maintenance of your mood*”

with medications". The psychiatrist confidently informed me: *"You will never work and never be a valuable member of society"*. Other psychiatrists agreed with the diagnosis and prognosis. They also informed me that it was unlikely that my marriage would last and that I would not be able to raise my children. This prognosis and diagnosis caused a worsening of depression and shame.

After hearing and accepting the diagnosis I grieved deeply for who I was, who I thought I was 'never going to become' and for my family. I remember telling my psychiatrist *"I thought I was born to do something special. To make beautiful art and bring joy to the world"*. The psychiatrist's response was, *"No, you are just mentally ill. People with Bipolar often have these delusions. You need to lower your expectations of what you can achieve"*. I understand these things were said out of concern for me. However, they were a damning sentence to hand down.

The medications I was forced to take made me feel unwell, foggy and only half alive. Within two months I had put on 22 kilograms and had developed a shake in my hands and body. This neurological condition has worsened over the years. When I explained how the medications made me feel, I was informed that the priority was for my mental health to improve, rather than being concerned about the harmful side effects on my body. It still seems irrational to me that our mental health is expected to improve as our body expands and our health deteriorates.

I saw myself as a victim of my abusers, my diagnosis, enforced treatment, decaying body, society's biases, discrimination, and my prognosis.

When I reached the age of 40, a peer worker compassionately challenged me to shake off the imposed low expectations of psychiatrists, family, community and myself. They encouraged me to shed the mantle of victimhood.

Trauma and victimhood alienate us from our potential, from who we innately are. It can also cause acute distrust of others and alienates us from intimate relationships and society. It can prevent us from claiming our human rights including the right to be responsible citizens.

The peer worker's empathic challenges helped me realise that I was allowing the abusers to continue the abuse even when they were no longer physically in my life. When I told the peer worker the psychiatrist's prognosis for

my future, her gentle challenge was *“I have the same diagnosis as you, but I work and meet my responsibilities. Why can’t you?”*

Although I had never previously held permanent employment, within a short time of being ‘awoken’ by the peer worker, I became a peer worker in the service I had been treated in.

The peer worker helped me take the first steps in the long journey of finding myself, apart from the trauma and pain. She helped me reframe my narrative.

Over the past 20 years, through my work, I have regularly delivered keynote speeches at conferences about living with trauma and mental health issues, advocating for humane treatment, the abolishment of seclusion and restraint and for positive changes in mental health services, workplaces and society.

In telling my story, I endeavour to never cause vicarious trauma by telling people details of what happened to me. I simply say, *“I was sexually abused as a child between the ages of 4 and 8, and as an adolescent”*.

One conference I spoke at was for people with lived experience of abuse, trauma, mental health issues and many were asylum seekers. Several people were supported by interpreters.

While I was speaking, one lady stood and walked towards the stage, with her interpreter accompanying her. I asked the woman if she wanted to say something and if she would like to use the microphone. She alighted the stage. This brave lady explained that she had lived in Australia with her children as asylum seekers for five years. She was from a war-torn country in the Middle East and she and her children had been raped as a weapon of war. She said *“Since living in Australia, I felt that I would never be able to return to my country of origin, but could never call Australia home”*. She explained that she felt ashamed of what had happened to her and her children and that she did not know, until she heard my story that these *“Terrible acts happened to women and children in Australia”*.

Another lady came forward with her translator and shared a similar experience, then another. The staff moved to ask the people to regain their seats. I said, *“No. Please do not stop this. This is important. Let the people speak. My story is no more important than their’s”*. For safety sake, I asked the

group to step off the stage. We took the microphone with us. More people joined us declaring what had happened to them.

Not all people were asylum seekers; some identified as being transgender, bisexual, gay or lesbian, some were Muslim, some devout Catholics, some Aboriginal people and some had disabilities. No-one shared details, they only declared that they too had been raped and sexually assaulted and were victims of trauma.

The group grew until approximately thirty people were all holding each other and crying tears of pain, empathy, love for each other and relief in the connection and shared vulnerability. I thanked the people for being so brave and open to sharing and acknowledged that others there may have similar experiences but did not feel that they could come forward.

The first lady asked for the microphone again, we embraced again as our tears flowed and I passed it to her. She said *"Now I know that this has happened to you and to other women and children in this country, now my children and I can call Australia our home."* I never expected that what had happened to me as a child, decades later, could help a lady and her children to feel a belonging and connection, to feel that Australia is their home. I felt deeply blessed to experience something beautiful emerge from our pain.

This experience and story shows that people can find healing through purposeful sharing of lived experience and vulnerability. Shared vulnerability is a strength, not a weakness. It can connect us in a way that nothing else can. This is a basis of peer work and an important part of healing.

I often explain that people are like beautiful Kintsugi bowls. Kintsugi is a Japanese craft and philosophy in which broken vessels are mended with melted gold that hardens and holds the pots shape. Japanese people believe the vessel is more valuable after it is broken and mended. The value is in the story of what happened to it, and in the cracks the gold has filled and mended. They are beautiful.

This is a wonderful metaphor for people with lived experience. We may have been 'broken', 'cracked and damaged' but when we use our lived experience in the service of others, we heal and we aid healing in others. Pure gold.

The construct of a 'medical diagnosis' or 'mental illnesses' to replace and displace the natural responses to trauma, disempowers people with lived experience. However, it empowers clinicians and the community to negate their responsibility to prevent trauma and walk beside a person as they feel their pain, wrestle with it, reframe, heal and cast off the victimhood and illness. Clinicians, and society, can 'legitimately' situate the 'problem' within the individual if it is 'their mental illness'. Blind acceptance of the medical model and diagnosis, by the community, enables the perpetrators of trauma and communities to wash their hands of the responsibility of the abuse, 'illness' and of those of us who are called 'the mentally ill'.

Trauma, the subsequent victimhood, the imposed medical diagnosis and treatment, and low expectations robbed my family, my community and I of all that I had to offer until I reclaimed my social citizenship and my right to be responsible.

Over the course of my lived experience career I have been a Peer Worker, Manager of Peer Workers, Director of Consumer, Carer and Community Affairs for the same public mental health service. I was appointed as the Inaugural Deputy Commissioner with the New South Wales Mental Health Commission and I founded Vision In Mind, a mental health training and consultancy business. I am currently the General Manager, Inclusion for Flourish Australia; a large community managed specialist mental health organisation.

All of these positions have been designated lived experience positions in which I was required to use my lived experience purposefully. I feel honoured to have had these opportunities to serve my lived experience community. Along with raising my children, my career has given me meaning and purpose. I have cast aside the '*low expectations*' of what I can achieve.

Prevention of trauma and mental health issues is the 'Holy Grail'. It is imperative that we prevent the sexual, physical and emotional abuse of children, teenagers and adults if we are to prevent mental health issues and decrease suicides. However, we must also work to deconstruct the marginalisation of people through diagnosis and treatments which further traumatise and medicalise what has happened to us.

Supporting people to understand that their 'symptoms' are those of trauma rather than illness can lead to people feeling differently about themselves. For

many people with a diagnosis listed in the 'serious and enduring' spectrum of medically constructed diagnosis or disorders, the expectation of many is for only a minimal level of 'recovery' and 'maintenance of mental health'. However, much more is possible. Multitudes of people in the lived experience community prove this on a daily basis. If people are still to be inflicted with a diagnosis, then let that diagnosis be considered only as a form of post-traumatic stress disorder and that our symptoms only reflect the natural response to trauma and life events. May our supports be provided by people who have had similar experiences, and who connect with us in shared vulnerability but who emulate healing and hope. May all of our service interactions be trauma informed, compassionate and person-led.

People impacted by trauma and subsequent mental health issues need healing and the ability and opportunity to reach our full potential in all areas of our lives. Our families, workplaces and communities need the ongoing opportunity to enjoy all that we have to offer. Our lives may have been shattered at one or many points in our lives; however, great beauty can come from our experiences, pain and healing. What we have to offer others can be pure gold. All communities, across the world, need to be enriched by this gold.