

Speech by David Braniff, SANE Speaker, at the launch of People Living with Psychosis 2010

Parliament House, Canberra. 23 November 2011.

I have been asked to speak today and appraise this report. That's easy: I love it. I hope this report becomes a people's report where interested people have a look at information that may have great relevance to them.

I congratulate its commissioning and the work that has gone into it. It is a massive survey and provides the Government with a level of understanding needed to shape future policy and practice and any future mental health reform. The psychosocial nature of the report has profound implications if we understand all of its considerations.

As I read this report I kept ticking 'yes' in my mind – all the time. Yes that's right, yes that's right. It almost mirrored my past 14 years and resembled a research document of my psychosis experience and recovery journey. I was also encouraged to describe a way forward. How do we turn this report into real reform – from the perspective of the people it contains?

Main survey points

This report shows incredible levels of pain and hardship among people who live with the condition of psychosis. It shows many people do not live with a cure, but a will to live a normal, rewarding and productive life under trying circumstances. Frightening levels of 'deterioration' of functioning jump out of the report. There is severe negative impact on many areas of daily life. Education, employment, housing, health, finance and social isolation are all affected. The report shows the impact of psychosis is more about lifestyle factors and issues of the 'human condition' than just the psychiatric symptoms. These people are living just as much – if not more – of the human experience, which is common to us all.

The more you understand psychosis and people's experiences with it, the clearer it becomes that we are all working towards the same fundamentals of living a rewarding and productive life. We all wish to live with dignity, have a sense of belonging, a sense of momentum that our life is moving forward and to live with purpose.

Isolation and social exclusion

I think the findings on social difficulties faced are one of the most moving revelations to come from this survey. It was so sad to read data which shows the level of loneliness and social pain experienced. By nature humans are social creatures. Social contact is fundamental to life.

There is a horrible Catch 22 relationship between mental illness and isolation. Do not be mistaken: isolation can contribute to psychosis. Isolation works in three phases: isolation from the community; isolation from family and friends, and isolation within yourself and damage to the 'sense of self' – which is vital for life. Rewarding social contact dictated the course of my 'recovery' and I know the difference a caring society can make.

Emotion

The biggest 'delusion' that occurs in a psychiatric ward is the assumption that you can treat psychosis purely as a science. I'm here to tell you 'it is far from a science'. A psychotic onset causes great emotional trauma and is often a contributing factor in it. I have seen it time and time again. The psychosis exaggerates emotional trauma and this can become a crisis as well. In the clinical system very little attention is given to ordinary human experience and the effect of psychosis on the emotional self. A major factor in my recovery was my own patient brand of emotional therapy. It was important to care for and appreciate all of my experiences.

The 80:20 Rule

I want to tell you about my own '80:20 Rule' with mental illness. It is a concept that separates psychiatric symptoms and issues from life factors or human condition issues. Many find it useful to understand the landscape of treatment and the path towards recovery. If you look at 100% of the hardship that my mental illness caused me, only around 20% was caused by symptoms, that is: hearing voices, delusional thinking and the myriad of hallucinations. The majority of the negative impact on my life, that is 80%, came from the damage caused to my world, my sense of self and my relationship to the community. My everyday life and social connections were turned upside down and this is what caused most of the pain.

www.sane.org/mobile Mobile site developed specially for iPhones and similar devices. www.itsallright.org Youth website helping young people. mental illness. my family, my story.



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I experienced fractured relationships with other people; loneliness; inability to relate to others; a damaged career; being very overweight; terrible self-esteem and low confidence; social isolation; inadequate housing; disconnection from the community; reduced social activities; high anxiety levels; lack of money, and general low standing in society.

All this is what I really had to recover from. As you can imagine recovery from this was a massive job. The process started ever so slowly in the year 2000. Only 20% of my recovery was from symptoms of psychosis. Therefore a psychiatrist can only assist with this 20%. The '80:20 Rule' is a very common theme with people that have a mental illness. Just like me the majority of their hardship is with everyday life. This illustrates the amazing thing about mental illness and the community. Everybody in the community is in a position to help with the majority, the 80% of the trouble.

We can all play a very important role in any number of ways and I will tell you honestly that in some cases your assistance will be far more important than the treating psychiatrist. By just being your good, kind self you can make an incredible difference.

To close

If we want to look forward, we should look first to the people this report is about. Generally when people enter an Adult Mental Health psychiatric ward, run by the State government, they have a personal crisis. For them there are three phases of their condition. There is the buildup (pre-crisis), the crisis itself, and hopefully the recovery journey. I have 'lived experience' of all three and have worked in the recovery phase for three years.

Each phase should have a complete system that concentrates on all pertaining issues in its entirety. A very visible 'brand name' of each system would promote greater public education, awareness and access. Anything we do should be intrinsically connected to raising the level of understanding within the community and awareness of the real issues. The power and benefit of educating the community cannot be underestimated. The effects would be profound and the single biggest effect the government can have on all three phases, especially 'early intervention'.

So many people fall through the cracks in the system because there are so many holes to fall through. It is really hard for the public to find available services when needed most. In many cases – especially in rural and remote areas – available support is almost invisible. Centralised, coordinated and very visible service delivery would have a great benefit.