

I never wanted to just sit around smoking cigarettes and drinking coffee

Andrew Voyce

Abstract

Purpose – *Essay asks questions about people with schizophrenia and recovery.*

Design/methodology/approach – *The essay is written in an autoethnographic style.*

Findings – *The purpose of this paper is to portray the actual outcome for a person with schizophrenia, in the context of recovery and the achievement of independence.*

Research limitations/implications – *Statistics are from review of various sources and are compared with autoethnographic data. The implications are to confirm social exclusion for the cohort of people with schizophrenia.*

Practical implications – *Practical implications include the recognition of the unusual destinations for those with schizophrenia.*

Social implications – *Independence is a desirable and much espoused social outcome and yet so few people with schizophrenia are empowered in this way, meaning that they fail to share a social dialogue with many of their fellow citizens.*

Originality/value – *This essay details a struggle to live up to social norms which are hindered because of a life with schizophrenia.*

Keywords *Work, Schizophrenia, Mental health, Recovery, Working age adult*

Paper type *Viewpoint*

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There is no doubt about the beneficial effects of work for mental health. Having a work life is strongly associated with well-being, and conversely worklessness is associated with poor mental health. “The benefits of work are most apparent when compared with the well-documented detrimental mental health effects of unemployment” (PubMed.gov, 2022) For people with schizophrenia, as I am, there is a clear picture around working life, and I will comment on aspects of work and psychosis in this essay. Schizophrenia is a condition beset by stigma and prejudicial perceptions. Allport (1954) created the ladder of discrimination, which starts with prejudicial language and builds up through avoidance to active disadvantage and discrimination. The very term schizophrenia can be enough to set in train poor outcomes and opportunities. I will discuss some general themes and relate them as the context of my personal journey through troublesome thoughts, false beliefs, delusions and a non-consensual view of reality (Voyce, 2021).

The general picture for those with schizophrenia and recovery is not an optimistic one. For the 1% of the population who have schizophrenia, many sources give four destinations. The Royal College of Psychiatrists (2022) in the UK, Schizophrenia.com (2022) in the USA and other sources say that 10% of people with schizophrenia will be deceased within 10 years of a diagnosis. Sometimes people with schizophrenia take their own lives, and indeed after becoming psychotic and in my chronic association with the mental health system, I have attempted suicide. Perhaps 15% of people with schizophrenia will not respond to therapies and will be looked after in hospitals and halfway houses in the community. Indeed, my years as a working age adult included a total of six years spent in state mental institutions and a

similar number of years in community homes, run by local government, charities, religious organisations and private owners. Expectations in these places were to live on social security and sit around smoking cigarettes and drinking coffee. Another destination for people with schizophrenia is to be on a recovery journey from these places, to a place where they can be considered to be recovered:

Q1. What does this mean?

Q2. What does recovery mean?

I adhere to definitions of recovery that include effective therapies, a meaningful life, empowerment, hope and above all an identity beyond that of mental patient ([Scottish Recovery Network, 2022](#); [Drennan and Alred, 2012](#); [Watson and Meddings, 2019](#)). The proportion of people with schizophrenia who can be deemed recovered is commonly put at 25%. Most people would agree that to be recovered and to lead a satisfactory life in the community, we need to be independent: It is a virtue to better yourself and to better help you control your life ([The Hidden Dominion, 2017](#)). In today's world, there is only one route to independence and that is through work. Most people with schizophrenia wish to work, they wish for independence, choice and empowerment ([The Atlantic, 2015](#)). Most people with schizophrenia would accept this as an outcome. Yet only 25% of people with schizophrenia can be designated as recovered and many fewer are in work.

Let me add this into the mix. Some figures suggest that only 10% of people with schizophrenia are in work. A review of information in the public domain reveals this, perhaps in the absence of rigorous national statistical data ([Living with Schizophrenia, 2022](#)). So:

Q3. How can this be that 25% of people with schizophrenia are counted as recovered, yet so few work?

Q4. Why is it that so few people with schizophrenia have the option of independence through work?

If 1% of the population have schizophrenia, that means that in the USA, 2.5 million people have schizophrenia and that in the UK 600,000 people have schizophrenia. If under 10% of people with schizophrenia are in work, that makes up a large proportion of the burden of unemployment from people with schizophrenia. This seems to be an extremely unsatisfactory and undesirable set of outcomes for our socially excluded group:

Q5. What does it mean that 25% of people with schizophrenia are recovered?

[MedAlertHelp \(2021\)](#) in the USA says that an essential statistic for 2022 is that 20% of people with schizophrenia are recovered in the sense of managing their symptoms. [Living with Schizophrenia \(2022\)](#) in the UK says that 25% of people with schizophrenia recover, without giving a definition of what they mean by "recovery", whereas the British [Royal College of Psychiatrists \(2022\)](#) gives a similar figure for those in recovery, which they describe as "getting better". I think there will be some common ground with those who offer more radical definitions of recovery in schizophrenia, although these models are not always accompanied by statistics on those described. Seminal definitions of recovery include the late [Anthony's\(1993\)](#) text: "It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness." Anthony did not specify the numbers included, nevertheless his definition is held in high esteem in recovery literature. Many will recognise and concur with the [Priory \(2022\)](#) Group, who say that recovery is not about a cure and goes beyond symptom management, to social recovery. However, the Priory Group does not have a figure for those in this cohort. There is a separate argument where recovery is mentioned as above and with the statistics on people with schizophrenia who work. Whatever the context, figures for those with schizophrenia in work were given as: 10%–20% by SpringerLink in 2004 and 10.24% by National Library of Medicine for 2016. These are an ongoing set of similar statistics which do not change over time. There remains

a gulf between the numbers of people deemed as recovered and those with schizophrenia who are in work.

I can look back on 47 years as a working age adult between the ages of 18 years and retirement age at 65 years. I believe that I developed schizophrenia in my late teens, so my years of adulthood have been blighted by psychosis. During that time, I actually worked for less than eight years. That is about 18% of those years, and that looks like par for the course compared to general statistics for work and people with schizophrenia, if not slightly better than the average.

I put the start of psychosis in my life firmly in the context of cannabis smoking. This I associate strongly with the onset of paranoia and negative effects such as self-neglect. Later on in my life this was to develop into a whole litany of non-consensual views of reality. These included that the Russians were coming, that traffic was following me around because of a transmitter I had on me, that Morse code signalling was going on everywhere, that my ID had been stolen and other unhelpful beliefs. These beliefs punctuated 20 years of my life as a revolving door psychiatric patient, even though by later in my adulthood I had given up smoking cannabis.

The cannabis smoking took place at university when I had access to funds. I was not concerned that I was spending all my assets on buying large amounts of drugs, because at that time in the late 1960s and early 1970s we had the full employment economy ([BBC News, 2011](#)). I learned how this worked at economics classes and I fully believed in this revelation of Keynesian theory. In those days, jobs were easy to come by and I was not worried by spending money that could have bought a small house, because I fully believed that I could get a job whenever I wanted in this era of the full employment economy. All I would need was a regular amount of money to pay the bills and smoke cannabis. However, I was becoming extremely paranoid, especially in lecture theatres, where I had guilty thoughts that everyone knew that I had been wasting my time smoking cannabis and that I had not done any reading for the course or written any essays. I felt I should not be there and eventually failed the course. Then unfortunately Keynesian economics ceased to work and jobs were hard to come by and were lowly paid. My paranoia and destitution led me to be admitted to a mental institution. I spent 20 years as a revolving door patient and had three jobs in that time.

I realised my mistake of not buying a house when I could have done, and during my years in and out of institutions, I was consumed by the need to get a job with enough income to buy a house. Unfortunately, I could only get menial clerical work and I would constantly be doing sums to see if I could buy a house. I worked as a clerk in local country towns. At that time there was a formula for getting a mortgage to buy a house, whereby it was possible to borrow three times your annual salary to buy a property. I would start a job on a low salary and at that time in the 1970s and 1980s we had high levels of inflation ([Inflation Tool, 2022](#)). My original intention to get promoted to a better pay band never came about, and what was most unhelpful was house price inflation, “screaming away” at 30% or more each year. I could never catch up. Another complication was that it was necessary to put down a substantial deposit to enable a mortgage contract. I saved up my social security benefits in hospital, however with house price inflation my savings were never enough. Looking back, I could have gone on a nice holiday at least rather than keeping on this fruitless quest to get on the property ladder, which relatives of my age seemed to do with ease. I felt constantly left behind.

The result of this combination of menial work and destitution impacted on my well-being and reacted with my constant struggle with the medication given in the asylum institutions. I was always treated as non-compliant which resulted in medication which was administered by injection. A side effect called akathisia followed, causing chronic restlessness for seven days after the administration of an injection, so aptly described by Jack Henry Abbott

(Wikipedia, 2022). What work meant to me was an opportunity to escape supervision either from the mental institution or in the community home, from having medication by injections. Coupled with the impossibility of achieving my financial aims and buying a house, and the dreadful akathisia, I would reach a point of no return. I would take what resources I had in the bank and quit everything – job, hostel, whatever. I would live rough in a car and often had a brush with the law. This would result in a return to the asylum where the same failed treatment would be reinstated.

At last, I achieved my ambition to own a house. This was in the early 1980s after I had been resettled to London. The pay there was a lot better and I managed to buy a house in the cheapest area. This could have been the fulfilment of my dreams and all my hard saving, however all it meant was another way in which I could escape supervision to have the injections. So, in due course I became psychotic, was made redundant and the house was repossessed.

After the following inevitable hospitalisation, I negotiated to have medication by tablet. This has led to 30 years of life in the community without hospitalisation or homelessness. I am happy to live without delusions or paranoia and have a tenancy on an apartment in social housing. I am now no longer driven by impossible aspirations. Perversely, since reaching retirement age at 65 years, I have had part time work in peer support. Coupled with my state pension I now pay all my bills without recourse to means tested benefits, I am independent and pay taxes, however that home ownership still eludes me.

Two of us started as peer support workers in 2016 in a forensic hospital, and there was the time when the two of us were on our own in a nursing station with a full set of keys. After the Fun Boy Three song (Songfacts, 2022), that meant that “the lunatics have taken over the asylum!” No, we did not let everybody out and we did not raid the safe and the medical cabinet.

So, this is what a lifetime looks like following on from the onset of schizophrenia. It is what those statistics look like in real life.

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