Gavin Mooney Memorial Essays 2014

The Social and Cultural Determinants of Mental Health

collective responsibilities, individualism, austerity and entitlements

El Gibbs
Malcolm Forbes
Olivia Hibbitt
Sandy Jeffs & Margaret Leggatt
Stephen Wright

INSIDE STORY   croakey   THE UNIVERSITY OF SYDNEY

Contents

Preface

T he Gavin Mooney Memorial Essay Competition honours the work and memory of the late Professor Gavin Mooney, a health economist who was a tireless advocate for social justice in local, national and international arenas. Each year the competition calls for entries related to a theme around equity and social justice.

Launched in 2013, the $5000 competition is a joint project of the Sydney School of Public Health at the University of Sydney, the public health blog *Croakey*, and *Inside Story*, an online current affairs publication from the Swinburne Institute for Social Research. It seeks to draw public attention to social justice and health equity concerns, and to recognise the public-interest value of writing and writers.

The 2014 competition called for essays on the theme "The social and cultural determinants of mental health: collective responsibilities; individualism; austerity; entitlements."

Out of twenty-three entries, the winner was "A Place to Call Home: Housing Security and Mental Health," by freelance writer El Gibbs. Runners-up were Malcolm Forbes, a medical registrar and researcher; medical writer Olivia Hibbitt; poet Sandy Jeffs and sociologist Margaret Leggatt; and Stephen Wright, a writer and counsellor.

The competition was judged by Gomeroi writer and blogger Kelly Briggs (also known on Twitter as @TheKooriWoman);

Peter Browne, Editor of *Inside Story*; Professor Shane Houston, Deputy Vice-Chancellor (Indigenous Strategy and Services) at the University of Sydney; Professor Glenn Salkeld, Head of the School of Public Health at the University of Sydney; and Melissa Sweet, moderator of *Croakey*.

The judges sought works that:

- are disruptive – challenging or prompting change in the status quo
- incorporate novel ideas or approaches or thinking or style
- tell stories that matter
- are well-written.

In addition to publication in this collection, the winner is published at *Inside Story*, insidestory.org.au.

CHAPTER 1

A place to call home: housing security and mental health

El Gibbs

House prices are booming in major city centres across Australia. Increasing numbers of investors use tax concessions such as negative gearing, which raises the prices of existing properties. Home ownership is falling among first home buyers and rents have exploded in traditionally affordable suburbs. This combination of factors has a direct impact on vulnerable people, such as those with a mental illness, by putting safe, secure housing out of reach.

The tax treatment of housing disproportionately favours those who own, rather than rent, property. This inverts Australia's usually progressive tax regime, as those who are already wealthy receive far more benefits than those who are not. And because housing is often the major asset in a family, inability to afford housing just entrenches inequality. For people with a mental illness, insecure tenancies, low incomes and rising housing costs work against their recovery and wellbeing.

This inequality must be urgently addressed as part of broader social reforms for people with disabilities, including psychosocial disabilities. Without a home that is affordable,

people with a mental illness can end up in prison, or become homeless.

People on low incomes, many of whom have mental health concerns, are being pushed further and further away from services that people on higher incomes take for granted. If people can't get access to healthcare, are we permanently consigning them to life at the bottom? How can people recover from mental illness if they don't have a place to call home?

•

I first met "Mary" through her music. Late one night, tired from my commute to Sydney, I sat on my back verandah in the Blue Mountains, drinking a glass of wine and smoking a cigarette. The mist had drifted up slowly until all I could see was the faint glow of the moon and the reflection of the streetlights. And through that mist came the sweet sound of Nina Simone, layered over prickly jazz chords.

Mary loved this kind of music; all spiky crescendos and loud wailing brass. Her battered old record player would start up downstairs about nine most nights as she worked through her collection. Occasionally, the needle on the player would get stuck, and small fragments of notes would repeat, and repeat.

It was months later when I finally met my neighbour in person – my commute meant I was rarely home during the day, and asleep by the time she cranked up the tunes each night. But she often took my bin out or brought it back in. One rare weekend at home, I came back from the supermarket, and there was Mary sitting on her doorstep.

She was a tiny lady, all fine-lined skin over pointy bones; thin white hair fading from blonde and bright blue eyes. It was a cold morning, but she was only wearing a t-shirt and skirt. I said hello and she jumped; far away in her thoughts, she hadn't even noticed I was coming past. I smiled and told her how much I liked her music. It took a while to convince her that I meant it. She lit a cigarette; I put down my shopping bags and did the same.

Over the next few years, Mary and I often had a cigarette on the doorstep. She'd leave me presents when I was in Sydney; coming home, I'd discover a card, or a cake, or some flowers at my door. I'd leave groceries at her door when I knew I'd be away for a week or more. We gardened out the back of the house on those clear, cold and sunny Blue Mountains mornings.

I loved the mountains, despite the commute. I had room to breathe and space that I could never afford in Sydney. I'd trudge up Katoomba Street before six most mornings and let the rattle of the train down the hill lull me off to sleep. I loved the diversity of people in my town; rents were still low enough then that lots of different folks lived together, rubbing up against each other.

Affordable housing

Everyone needs somewhere to live, and yet housing has become just another way to make money. The idea of a right to a home seems quaint in a world of renovation programs and eye-popping auction results that are breathlessly reported in the major newspapers. But it wasn't always this way.

Previous Australian governments believed that affordable housing was not only important for individuals and families, but also valuable for the wellbeing of the whole Commonwealth. In 1945, a government report stated: "We consider that a dwelling of good standard and equipment is not only the need but the right of every citizen – whether the dwelling is to be rented or purchased, no tenant or purchaser should be exploited for excessive profit."[1] Public housing was integral through to the 1970s to ensure a degree of equity. By the mid 1960s, one in five Australians lived in public housing.

Over the last two decades, housing has become less and less affordable. Inner-city areas, close to services and work, have become gentrified and expensive. This is more than just the market at work. Government policy now is to favour those who already own property, through negative gearing and capital gains

tax concessions, while doing little to support renters, particularly those on low incomes. Governments at all levels have also stepped far away from being direct providers of housing, with new public housing falling to its lowest level in 2007.

The Grattan Institute reported in 2013 that tax concessions worth $36 billion a year went to subsidising those who own property and a further $7 billion went to investors for negative gearing. By contrast, low-income tenants received $3 billion a year in rental support.[2]

Finding somewhere to live in Australia's major cities is becoming harder and harder, especially for people on low incomes. Anglicare's affordable housing snapshot this year found that someone on Newstart or the Disability Support Pension could not find an affordable home anywhere in Sydney. For people eligible for public housing, the waiting period can be longer than a decade and social housing, provided by not-for-profit groups, is also in short supply.[3]

Research from SANE Australia shows that many people with a mental illness live on a low income, with one third receiving below $20,000 per year; SANE also found that they contend with high health expenses. Both factors clearly increase their reliance on affordable housing.[4]

Social and public housing are important options for people with a mental illness. But increasingly tough entry requirements for public housing mean that many more extremely disadvantaged people are housed together, further exacerbating health-related disabilities. People with a mental illness report increased anxiety and other symptoms because of the marginal nature of public housing.[5]

Boarding houses have thus become the default housing option for many people with mental illness, particularly following the closure of large institutions. Despite recent NSW reforms to boarding houses, they remain an insecure and sometimes dangerous place to live. These houses are outside the regular

tenancy system and provide poor facilities; residents are often exploited and in poor health. Some reform to this system has finally begun, but as recently as 2012 ABC Radio's *Background Briefing* reported on the deaths of six residents due to neglect.[6]

At both state and federal levels of government, there are clear policy commitments to "housing first" approaches in mental health policy, which acknowledge that secure accommodation is vitally important. And yet little or no funding is allocated to creating that accommodation. Investment in public housing has dropped sharply over the last few decades. The now-abolished National Rental Affordability Scheme, which operated in 2008– 2013, gave developers incentives to build and rent lower-priced properties, but it only took affordable housing back to 1980s levels. With nearly half a million lower-priced housing properties needed, it was a drop in the bucket.[7] Given the competition for the few available places, is it any surprise that people with a mental illness end up at the bottom of the pile?

Housing is crucial to mental health, both for people with a mental illness and for those without. The most recent survey of renters from the NSW Tenants' Union showed they had high levels of anxiety; and this was particularly true for those in housing stress – that is, paying more than 30 per cent of their income in rent. People in both public and private rental properties were affected.[8]

The latest report from the Australian Housing and Urban Research Institute for the Mental Health Commission of New South Wales looked in detail at the links between mental health and housing. It noted:

> Social housing can no longer be relied upon as a housing solution for people with mental health issues due to shortages in supply. In order to account for these housing market problems, the private rental market is likely to represent the most important segment of the housing market for people with mental health issues.[9]

Rents, even in outer suburbs, have risen faster than the minimum wage, with the median rent in Sydney now above $500 a week. At the same time, people are renting for longer periods, and for more of their lives – one-third of tenants are over forty-five. Tenants have far fewer rights than their counterparts overseas: landlords can evict people for no reason, and there are no caps on rent increases.

People with a mental illness who are employed are more likely to be working part-time, and therefore earning a lower income. SANE Australia has found that people with a mental illness also experience discrimination at work and need a supportive employer.[10] These barriers prevent the increase in income necessary to make housing less precarious.

•

Katoomba is a tourist town and has been for over a century. Guest-houses line the streets, some now made over as backpacker hostels, some as private rental properties, and some as boarding houses. Behind the shops in Katoomba Street is a rabbit warren of small flats in various states of disrepair and often lacking documentation and regulation. As the Sydney housing boom continued and rents climbed further and further, more people arrived to try to find a place to call home.

And as they came, the people who already had a home here were pushed even further to the margins. Hotels became crisis accommodation, and more people were living in their cars or sleeping rough in the cold bush.

Looking back

In New South Wales, the landmark 1983 Richmond Report laid out the pathways for people with mental illness to move out of institutions and back into the community. This report highlighted what community resources were needed, and the discrimination faced by people with mental illness in accessing services. Richmond recommended that the government provide specific

housing allocations for people with mental illness and subsidise places in boarding houses.[11]

A decade later, the nationally focused Burdekin Report found:

> One of the biggest obstacles in the lives of people with a mental illness is the absence of adequate, affordable and secure accommodation. Living with a mental illness – or recovering from it – is difficult even in the best circumstances. Without a decent place to live it is virtually impossible… All the evidence considered by the Inquiry established that the policy of deinstitutionalisation cannot succeed unless it is complemented by appropriate policies on housing – and a commensurate allocation of resources.[12]

The lack of accommodation, over thirty years later, is still one of the biggest barriers for the independence and dignity of people with a mental illness. The failure to address the cost of housing is causing real harm in the community, while others get rich.

In 2002, the NSW Parliament Select Committee on Mental Health emphasised that people in public housing needed extra support to keep up with their rent, and suggested that specific housing be provided for people with a mental illness. In a statement to the committee that is very familiar, Mission Australia said that the Sydney housing market was "characterised by high rents, low vacancy rates and very high cost of home purchase."[13]

The 2003 Mental Health Council of Australia's *Out of Hospital, Out of Mind!* report also made this clear:

> There is a distinct lack of stable and appropriate housing for mental health consumers. When consumers are discharged from hospital it is not uncommon for them to be left without any accommodation options and end up on the street; it was reported that many consumers lose their

> housing during their hospitalisation. There was the concern that many boarding houses are closing and the criteria for eligibility for housing is getting harder.[14]

People with mental illness, advocates and carers have made this point over, and over, and over again. Yet current headlines are about which suburbs have cracked the one million dollar mark, instead of about how many people are being forced further and further from services and into substandard, insecure housing. For Aboriginal and Torres Strait Islanders, who already make up a higher percentage of homeless people, the situation is even more dire.

In 2001, a coordinated group of community sector organisations employed a health worker for twenty-five hours a week to work with people living in boarding houses in the Blue Mountains area. This followed from other projects, all short-term, that demonstrated the myriad problems for people with mental health disabilities living in these kinds of homes. Neglect, abuse and appalling other health problems were rampant. A report on the project noted:

> The "episode of care" model of health service provision with an emphasis on management of symptoms of "illness" rather than a more global view of "disability" can be seen to have failed many residents of boarding houses who constitute one of the most marginalised, passive and disenfranchised populations, least likely to initiate or maintain contact with service providers.[15]

•

In 2009, ABC TV's Four Corners *featured a program on homelessness in Katoomba. A motel converted to crisis accommodation; exploitative landlords; terrible boarding house conditions. None of these a surprise to people living there.*[16]

Committees were formed, action plans were agreed, and a few new properties were built. But the fragile links set up between support services, housing providers and people at risk of ending up homeless proved not enough to help Mary.

Mary's situation was what was meant to happen when the large psychiatric institutions were shut down in the 1980s. Her diagnosis of schizophrenia, which once condemned people to a life locked away, was no longer a barrier to her living in the community and having her music close by. Here, in her little, sparsely furnished flat, she could have friends over and stay up late dancing. Mary's case worker visited regularly, her medication helped smooth out the rough edges of her illness and people in the neighbourhood looked out for her, reminding her to eat when her dreamings took her far away.

She had been a teacher in a former life; her only child was in another state. I don't know how old she was, or how long she'd lived downstairs. When I asked, she told me that she'd always been there. She coughed long and hard, then had another cigarette.

Mental illness, homelessness and a secure home

People with a mental illness make up a large percentage of people who are homeless, and at the same time, homelessness contributes to poor mental health. Homelessness can include rough sleeping, overcrowded homes, couch surfing, and living in temporary or emergency accommodation. A study of people with a mental illness found there was a clear connection between stable, secure housing and their ongoing health:

> Housing is central to building a future. It offers a secure base. When that base is established, friendships, social networks and meaningful activities can develop. Consumers prefer housing that involves living alone or with a friend of their own choosing and having access to mental health support needs.[17]

The Australian Human Rights Commission links homelessness with a range of other rights, such as the right to health, privacy and personal safety.[18] One contributor to homelessness for people with a mental illness is their difficulty in maintaining a tenancy – in either public or private accommodation. The Homeless Persons' Legal Service found that people who were hospitalised sometimes lost their home, or were housed far away from their regular treatment centres.[19]

An innovative program, the Housing and Accommodation Support Initiative, or HASI, was set up in New South Wales in 2006 to bring together a range of services to assist people to maintain a tenancy and stay out of hospital.[20] HASI focuses on integrating services with housing, rather than the usual separation of housing from health and wellbeing. The majority of people using HASI have schizophrenia and are either homeless, or at risk of homelessness. The 2012 evaluation of the program showed a remarkable improvement in people's lives, with 90 per cent able to keep a roof over their heads. The report noted:

> Most people enter the program with a history of unstable housing, including almost half with no home immediately prior to entering HASI, for example, from hospital, prison, living with friends or family, living in a boarding house, in other unstable or temporary housing or primary homelessness. Many consumers who were already housed before joining HASI had also experienced unstable housing in the past.[21]

Housing is a key part of the submission from the Mental Health Commission to the proposed Strategic Plan for Mental Health in New South Wales, but to date there has been no commitment from the NSW government to increase the supply of affordable housing, or create further different models of social housing such as HASI.

•

A few weeks before Christmas one year, I got home from Sydney late one Friday night – the light tricking me into staying at the office longer than I had intended. Walking home from the station was a blissful relief from a day sweating in the sweltering heat on the plains. Checking the letterbox, I found a note from the real estate agency that I promptly ignored until the next day. I'm glad I did, because an eviction notice is never a good way to end the week.

The owner was selling the whole building, and we all had to get out. At Christmas. Of course they had every right to do that under the current law, but it was a punch in the guts to have to leave my lovely flat, with the wonderful verandah. And then I heard screaming.

The eviction notice broke Mary. I found her curled into the tiniest of balls on her lounge room floor, smashed records lying all around her. I rang the mental health crisis team and stayed with her till they came. There was nothing I could do to comfort her; she couldn't conceive of not being able to stay in her home. And the loss of her home took something else away from her – independence.

Mary never came back. Her meagre belongings were packed away and space found for her in a nursing home that specialised in psycho-gerontology and "secure facilities for wanderers." And I only knew that because the bloke at the tobacconist told me that Mary had come in after running away.

I only saw her once after that, passing her on the street. She didn't remember me – away from what was familiar, I was just another intrusive noise. I don't know if she has her music anymore, those soaring voices she'd accompany in fragile soprano tones.

•

Over and over reports are written about why housing is as important as having enough to eat, and just as integral to health and wellbeing. Yet they are ignored, condemning people on low incomes to poor health. A place to call home is more than a roof over our heads, or a way to make money. Secure, affordable

housing has to be part of all health policies, particularly for people with a mental illness.

Without a home, it's damn hard to get well and stay well.

Author

El Gibbs is a freelance writer who has written widely on disability and social policy. She has a blog, *Blunt Shovels*, and is @bluntshovels on Twitter.

Endnotes

1. "Women in Public Housing History," *The Brown Couch*, Tenants' Union of New South Wales, 10 September 2012, accessed at http://tunswblog. blogspot.com.au/2012/09/women-in-public-housing-history.html.

2. Jane-Frances Kelly et al., *Renovating Housing Policy*, Grattan Institute, Melbourne, October 2013, accessed at http://grattan.edu.au/report/ renovating-housing-policy/.

3. Anglicare, *2014 Rental Affordability Snapshot*, April 2014, accessed at https://www.anglicare.org.au/media-releases/2014-rental-affordability-snapshot.

4. SANE Australia, *SANE Research Bulletin 9: Money and Mental Illness*, July 2009, accessed at http://www.sane.org/images/stories/information/ research/0907_info_rb9money.pdf.

5. Jacqueline Le et al., "Mental Health and Housing: The Public Health Crisis No One Wants to Know About," *Crikey*, 10 August 2011, accessed at http://www.crikey.com.au/2011/08/10/mental-health-housing-the-public-health-crisis-no-one-wants-to-know-about/.

6. Wendy Carlisle, "Boarding House of Horrors," *Background Briefing*, ABC Radio National, 24 June 2012, accessed at http://www.crikey.com. au/2011/08/10/mental-health-housing-the-public-health-crisis-no-one-wants-to-know-about/.

7. Australians for Affordable Housing, *Get the Facts*, 2015, accessed at http://housingstressed.org.au/get-the-facts/.

8. Ned Cutcher and Leo Patterson Ross, *Affordable Housing and the New South Wales Rental Market: 2014 Survey Report*, Tenants' Union of New

South Wales, April 2014, accessed at http://intranet.tenants.org.au/print/policy-papers/AHS-final-report.pdf.

9. Lauren Costello, Melanie Thomson and Katie Jones, *Mental Health and Homelessness: Final Report*, Mental Health Commission of New South Wales, June 2013, accessed at http://nswmentalhealthcommission.com.au/sites/default/files/publication-documents/Final%20Report%20-%20AHURI%20-%20Mental%20Health%20and%20Homelessness.pdf.

10. SANE Australia, *SANE Research Bulletin 3: Employment and Mental Illness*, June 2006, accessed at http://www.sane.org/images/stories/information/research/0606_info_rb3.pdf.

11. Department of Health, New South Wales, *Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled* (Richmond Report), March 1983, accessed at http://nswmentalhealthcommission.com.au/node/1521.

12. Commonwealth of Australia, Human Rights and Equal Opportunity Commission, *Human Rights and Mental Illness: Report of the National Inquiry Concerning the Human Rights of People with Mental Illness* (Burdekin Report), October 1993, accessed at http://apo.org.au/research/national-inquiry-concerning-human-rights-people-mental-illness.

13. New South Wales Parliament, Select Committee on Mental Health, *Mental Health Services in New South Wales: Final Report*, December 2002, accessed at http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/f742b6b2e561abdeca256c73002b7f87/$FILE/fullreport.pdf.

14. Grace Groom, Ian Hickie and Tracey Davenport, *Out of Hospital, Out of Mind! A Report Detailing Mental Health Services in Australia in 2002 and Community Priorities for National Mental Health Policy for 2003–2008*, Mental Health Council of Australia, April 2003, accessed at http://mhaustralia.org/publication/out-hospital-out-mind.

15. Lynn Godfree and Ian Bridges-Webb, *Boarding House Health Promotion Program: A Collaborative Model*, n.d., accessed at http://archive.mhcc.org.au/documents/LynnGodfree.pdf.

16. Sarah Ferguson, "The Last Chance Motel," *Four Corners*, ABC TV, 21 September 2009, accessed at http://www.abc.net.au/4corners/content/2009/s2689938.htm.

17. Graeme Browne and Martin Hemsley, "Consumer Participation in Housing: Reflecting on Consumer Preferences," *Australasian Psychiatry*, December 2010: vol. 18, no. 6, pp 579–83, accessed at http://apy.sagepub.com/content/18/6/579.

18. Human Rights and Equal Opportunity Commission, *Homelessness Is a Human Rights Issue*, 2008, accessed at https://www.humanrights.gov.au/publications/homelessness-human-rights-issue.

19. Sam Sowerwine and Louis Schetzer, *Skating on Thin Ice: Difficulties Faced by People Living with Mental Illness Accessing and Maintaining Social Housing*, Public Interest Advocacy Centre Ltd, October 2013, accessed at http://www.piac.asn.au/sites/default/files/news/attachments/skating_on_thin_ice.pdf.

20. New South Wales Government, Housing New South Wales, *Housing and Accommodation Support Initiative*, n.d., accessed at http://www.housing.nsw.gov.au/Changes+to+Social+Housing/Partnerships/Housing+and+Mental+Health/Housing+and+Accommodation+Support+Initiative.htm.

21. Jasmine Bruce et al., *Evaluation of the Housing and Accommodation Support Initiative (HASI): Final Report*, Social Policy Research Centre, University of New South Wales, September 2012, accessed at http://www.health.nsw.gov.au/mhdao/publications/Publications/pub-hasi-final-report.pdf.

Why him?

Malcolm Forbes

Why, at the end of the day, do I swipe myself out, locking him in? Why am I the doctor, and he the patient?

Our lives are not dissimilar. We were both born in 1987, with a healthy complement of genes. We had both shone in primary school for our sporting ability and then abandoned our sporting potential in secondary school in an act of rebellion. We had both experienced sadness over girls who hadn't reciprocated our love. We both found solace in the songs of Billy Bragg.

Andrew had grown up in a regional town in Queensland, as I had. The son of a miner and retail worker, he had enjoyed a middle-class existence, just as I had. The more I learned about him, the more the parallels emerged: the reasonable performance at school, the talent for football, the wide group of friends.

In 2000, our paths diverged. I had exhausted my second chances with the administration and was suspended from school. Andrew had been suspended too, from a school a few hundred kilometres south of me. However, my father was a teacher and had the wherewithal to get me back into the education system. With the support of my family I went back to school and got my life back on track.

Andrew wasn't so lucky. The year 2000 was his *annus horribilis*, the first of many. Each with new rejection; each new retreat

silently sealing his fate. He had gone from being the big fish in a small pond at his local primary school to a nobody at the nearby city high school. In attempting to establish his name, he became more boisterous and disruptive in the classroom. He still spent his lunch hour out on the sports oval, but had traded in his football and cricket bat for Tally-Hos and filters.

This change in behaviour reflected turmoil at home. His father was away at the mines, returning for only one week in every three. His parents' relationship had become more acrimonious and his eldest sister had moved out of home.

Then the watershed.

It was in the lead-up to Christmas. He had cleaned his room at his mother's request, in preparation for his father's return for three weeks' holiday. His favourite rugby league team, the Brisbane Broncos, had won the premiership that year. Andrew lay in bed on Christmas Eve, hoping for two things: that there wouldn't be any fights; and that he might get a Broncos jersey.

The knock on the door never came.

It took three days for Andrew to accept that his father wasn't coming home. In the weeks and months that followed he watched his already fractured life fall apart. He was shuttled between the family home and his grandmother's home as his mother turned to alcohol for comfort. The poverty that set in after losing their primary source of income was only worsened by the protracted legal battles of his parents' divorce. Andrew was alone.

Like a significant number of Australians, Andrew had experimented with marijuana before. Following his father's abandonment, Andrew started to use marijuana on a daily basis. Smoking offered him an escape: it filled the void left by his father and helped him erase his feelings of guilt about the role he thought he had played in his parents' separation.

Eventually, Andrew quit school. His inattention in class and constant truancy had led to his failing a number of subjects. At sixteen, as I was boarding a plane, heading overseas on a school

trip, Andrew was aboard one of Brisbane's graffiti-covered train carriages, traversing the southern suburbs aimlessly.

•

Andrew was admitted to hospital the night before I met him, by the overnight registrar. He had been found in his bunk at a local homeless shelter, breath shallow and complexion wan, slipping into the nothingness that follows three litres of Fruity Lexia and fourteen tablets of Valium.

The next day, cold light struggled to squeeze through the blinds covering the consultation room window. Andrew looked up at me momentarily. This consultation room, like all the others, was bleak. His eyes glistened as he responded to my banal question about his mood.

"I'm fucked," he proclaimed with resigned conviction.

This was an honest appraisal. His life had spiralled out of control over the past two years. He had lost his sister to a drug overdose. His other sister had frustrated the magistrate enough to send her to prison for a series of drug possession charges. He no longer spoke to his mother; or, more accurately, she no longer spoke to him. She had recently taken out a domestic violence order against him after he trashed her house in a drug-fuelled rage. He had been living what I documented in my notes as an "itinerant lifestyle." This was a palatable way of saying he had limited funds, no certainty about where his next meal was coming from, and no fixed abode. He had been living in temporary accommodation, his residential options constrained by the magnanimity of the local homeless services. He was a rolling stone, but had rolled right off a cliff and come to a heavy landing.

"I don't want to be here anymore. I'm fine. Just let me go."

I apologised. I explained my concerns, the concerns of my boss (his treating consultant), and the law. He looked at my shoes, his gaze steady, unwavering, despondent. He said nothing.

I saw him the following two days and we spoke at length. He was doing better. He accepted he was feeling low and had agreed

to start some treatment. We shared laughter and compared our music tastes. I revoked his involuntary treatment order but suggested it would be best for him to stay in over the weekend to have some time out. He agreed. We shook hands, and parted.

•

I walked out of the hospital doors and exhaled into the warm afternoon breeze. My first week as a psychiatry registrar had come to an end. The screeching galahs in the branches above reminded me of the cacophony of manic patients and dysfunctional family meetings I had left behind. While driving home, my mind wandered back to Andrew. Why him and not me?

I thought back to the explanation given by the consultant charged with my supervision. In a meeting that afternoon, where I discussed my challenging cases, he had disposed of that same question with the phrase "there but for the grace of God go I." Well, yes. Luck. Genetics. They surely played a role. But there was something so patently unfair about that explanation. It made what was so complex too easy. I didn't believe in fate, or any God, so I couldn't consign our disparate lives to the mysterious workings of some omniscient force. There had to be an explanation.

•

I didn't see Andrew again. There was a roster change and the next week I moved onto evening shifts. I heard from the inpatient registrar that his mental state had improved and he had been discharged. The consultant had confirmed my provisional diagnosis of adjustment disorder with depressed mood. He was started on Lexapro, a common antidepressant.

He won't take it, I thought.

Andrew's problems were not going to be fixed with a tablet. Especially one that takes a couple of weeks to start taking effect, only just outguns a placebo in terms of its antidepressant activity, and costs money – something that was increasingly scarce with the recent increase in the cost of cigarettes and reduction in Newstart.

He missed his follow-up clinic appointment. After discovering he had moved town, our hospital transferred his follow-up to another mental health service.

Despite all of this, I thought I'd done my job well. I'd arrived at the right diagnosis, my management plan had been acceptable, and he had been discharged. A good outcome.

•

On 25 October 2013, nine months after his discharge, Andrew tied an extension cord around his neck, tied that cord to the ceiling fan in his housing commission unit, and kicked the chair from underneath him. He was found by his girlfriend.

I didn't hear about it until the following month. A colleague informed me. "Do you remember that chap you saw in your first week of work here? The young Indigenous guy?"

"Oh yeah," I said. "Andrew. How's he doing? Has he been admitted again?"

"He's dead. He hung himself last month. We talked about him at the morbidity and mortality meeting this morning."

"Oh. Okay." I couldn't fashion an adequate response. My stomach sank and my mind clouded.

I couldn't concentrate for the rest of the day. I phoned my boss and asked if I could head home early as I was felling unwell. At home that afternoon, listening to Billy Bragg, I thought about him. Although I'd only spent ninety minutes with Andrew, I felt we'd established a solid rapport. I felt like I understood him. I felt he would have understood me had our roles been reversed. I wished the pious were right and that he was relaxing in some fair heaven. Tears welled up in my eyes.

I snapped myself out of it. Doctors, I reminded myself, must always maintain equanimity. Sir William Osler, the eminent Canadian physician and one of the fathers of modern medicine, had said this. It must be true.

Over the next few months, I forced Andrew to the back of my mind and got on with my daily work. I focused on distancing

myself from my patients. I was a good registrar: I was kind, compassionate, empathic, but I refused to allow myself to feel too much.

•

Since seeing Andrew, I have been faced with an assortment of sad stories from sad people. I do my job. I treat the acute issue. I attempt to help my patients build resilience. Most of my patients have good outcomes in the short term, but then their circumstances deteriorate and their wellbeing declines. Like all specialties in medicine, we have our frequent flyers.

My experience with Andrew, and dozens like him, shows me that what I do, and what we as doctors do generally, is not enough.

Australia has an excellent health and medical workforce. We have highly trained doctors and other health professionals. When patients are in our clinics and hospitals, their care is world-class. But what about when the patient goes home? We pay attention to every medical detail while the patient is in front of us. However, we absolve ourselves of responsibility when the patient leaves the clinic room or exits the hospital doors.

Outside of the hospital or health service is where the patient often needs our help most. This is where the pathology begins.

•

When it comes to mental illness, our focus is very much on the treatment of disorders once they are already established. The world is investing billions in developing new, high-tech treatments. This is despite our knowing a great deal about the preventable causes of mental illness.

We know that the poor and disadvantaged suffer disproportionately from common mental disorders and their adverse consequences. This disadvantage starts before birth and accumulates throughout life.[1]

Children from poorer families are at least two times more likely to experience depression or anxiety, all other things being equal.[1]

Extraordinary injustices and traumatic experiences, such as those inflicted on Australia's Indigenous people, can lead to psychological distress and mental illness.[2] Indigenous Australians still face racism in Australia, in addition to the multitude of other factors influencing the development of mental illness, including family breakdown, domestic violence, substance misuse, and social disadvantage.[3]

Indigenous Australians experience psychological distress at double to triple the rate of the non-Indigenous population, and have a suicide rate three times higher than that of non-Indigenous Australians.[3] Unemployment, fewer educational qualifications, lower income, adverse life events, smoking, and chronic physical illness all correlate with levels of distress.[4]

Stalin, so the story goes, said, "One death is a tragedy; one million deaths are a statistic." These aren't statistics. These are people like Andrew. Look at these risk factors and determinants and you see the factors affecting Andrew. He was an Aboriginal man, he came from a background of poverty and family breakdown, he misused substances during his teenage years, and when he died, he was living with unemployment and was on a low income on welfare.

For that reason, I believe his suicide was preventable. He was on the trajectory towards suicide for a long time. Our society failed Andrew, and we will continue to fail Australians – young and old, black and white – unless we address the inequities in social conditions that lead to mental illness.

To have any impact, doctors and other health professionals need to band together and make this a priority. If we could do it in Queensland for a contract dispute, then surely we can do it at a time when more young Australians are killing themselves than ever before.

We need to get in the ring and defend our patients. Not just when they're in our clinics, but also when they're under assault from our government. At the moment, the government

is attempting to paint a picture of a lazy and entitled population who make "poor health decisions." Personally, I've never seen a patient who started his or her life with a goal to make "poor health decisions" – to live a sedentary life, guzzle litres of booze, smoke a pack a day. These choices are, to varying degrees, products of our society. This is a call not to absolve individuals of responsibility, but rather to broaden our minds and consider the antecedent factors that lead to such health behaviours.

To blame those with mental illness for their problems is the cruellest barb of all. Mental illness saps our capabilities, including our capacity to command our senses, and our capacity to laugh, to feel that controlled rush of serotonin and dopamine. It saps our capacity to participate, to learn, to contribute, to make choices that govern our life. To blame individuals while they are suffering is to kick people while they're down.

The onus is on us, those in privileged positions who possess the majority of wealth and power in society. We've faced adversity ourselves, without doubt. But we are where we are through the support we have received. People often avoid expressing moral absolutes for fear of reproach. Forgive me, but I'm going to indulge here.

Extending support to those in need is the right thing to do, plain and simple. Thinking about the patient after he or she leaves your consulting rooms or hospital ward does not make you a bad doctor: it makes you a good human. Advocating for your patient, in all aspects of life that affect wellbeing, is part of your job.

Just as one doctor is often not enough to treat a patient with a complex illness, one government portfolio is not enough to manage the mental health of Australians. A cross-party, cross-ministry, cross-jurisdictional, collaborative response is needed. Easier said than done. But there have been too many Andrews who have left this world too early.

There has been excellent leadership in Indigenous mental health, and mental health more broadly, over the past twenty

years. We don't have to reinvent the wheel, we just have to put our resources behind the incredible women and men who are working day in, day out on this problem. We need to get a critical mass. It starts with us.

•

If I had been born with a different shade of skin, into a different family, I could have been Andrew. I could've been dead. If there were true equality of opportunity in Australia, and he had enjoyed the fortune of a supportive family, Andrew could have been me.

But he isn't, and he never will be. And that's why I need to make my voice heard, make my fortune count for something.

For Andrew.

Author

Malcolm Forbes is a medical registrar and researcher at the Cairns Institute. He has experience working in psychiatry as a principal house officer.

Endnotes

1. World Health Organization, *Social Determinants of Mental Health*, Geneva, 2014.
2. Ernest Hunter and Helen Milroy, "Aboriginal and Torres Strait Islander Suicide in Context," *Archives of Suicide Research*, 2006: vol. 10, issue 2, pp 141–57.
3. Kerrie Kelly, Pat Dudgeon, Graham Gee and Belle Glaskin, *Living on the Edge: Social and Emotional Wellbeing and Risk and Protective Factors for Serious Psychological Distress among Aboriginal and Torres Strait Islander People*, Discussion Paper Series No. 10, Cooperative Research Centre for Aboriginal Health, Darwin, 2009.
4. Anthony F. Jorm, Sarah J. Bourchier, Stefan Cvetkovski and Gavin Stewart, "Mental Health of Indigenous Australians: A Review of Findings from Community Surveys," *Medical Journal of Australia*, 6 February 2012: vol. 196, no. 2, pp 118–21.

Just cheer up: mental health in the age of austerity

Olivia Hibbitt

I remember the exact moment I first felt it: the overwhelming, crushing pressure of depression. It was one of those early summer days, where the warmth is gentle and the sunshine seems golden. The doors to my house were flung open and a slight breeze lifted the hair from my neck.

I was sitting in a patch of sunlight looking at the sleeping faces of my eight-week-old twins. I had two beautiful children, a job to go back to after maternity leave, a good education, a supportive partner and family, and enough money to feed and clothe myself, go on holiday and buy the things I wanted. Yet a dark grey fog surrounded me and none of this mattered. I felt like I was looking out at my life from the inside of a dirty bus shelter. In spite of all I had, I stood teetering on the edge of a cliff, at the bottom of which was an abyss of mental ill health.

One of the worst things said to me during that time was the ubiquitous, and seemingly innocuous, "You have two beautiful children, just be happy." Like mental ill health is just a case of weak personality that can simply be overcome by sheer force of will. Would similar accusations be levelled at diabetics? "You have

a pancreas, just make some insulin!" The truth I found during my brush with depression is that no matter what people say, the overwhelming societal view is that mental ill health is something that the individual must conquer. You must access the right services, you must recognise the signs yourself, and you must gather the last shreds of your self-worth and get yourself to the correct health professional; and then, once that happens, you must get better with no dallying. I didn't even think about talking to any health professional about my feelings. To do so would have been to admit to myself that I had a problem, that I wasn't the deliriously happy new mother that society had told me I must be.

Society and mental health: inextricably linked

I consider myself to be one of the lucky ones. I spent a few months standing at the edge of the cliff, but did not actually tumble over into full-blown illness. However, every year in Australia 4.5 million people will tumble over. In fact nearly one in every two Australians will experience mental ill health in their lifetime.[1] These statistics are bleak. They become even bleaker when one looks at the current political climate in Australia – where politicians speak of economic crises, of the end of "the age of entitlement,"[2] and of "leaners" and "lifters"[3]; and where mental health reform appears to be absent from the rhetoric and there is no longer a federal Minister for Mental Health.

For me, mental ill health was probably caused by a combination of pregnancy hormones, the pressures of taking care of newborn twins, and the deeply unsettling social isolation that accompanies motherhood. As someone who had been in full-time employment from the age of twenty, the change was sudden and catastrophic. However, while these factors may underpin many people's descent into depression, there is a much broader cause that is often talked about but rarely in terms of practical solutions. Social disadvantage is so intricately woven into health that there is no way to separate socioeconomic status from health

status. In fact, to turn it around, positive mental health is, at its core, ultimately determined by social and cultural factors. Positive mental health relies implicitly on a person's ability to contribute to society through his or her own self-expression.[4]

This fact is not a surprise. The role that socioeconomic factors play in health is no big secret; in fact the significant role that relative disadvantage plays in health has been known for decades. The seminal study on this phenomenon, the Whitehall study, began in 1967 and demonstrated that even in a population of relatively privileged civil servants in the United Kingdom there was significant disparity in health outcomes between those at the top and those lower down the pecking order.[5] Not only did this study empirically demonstrate the effect that social structure has on a person's health, it also demonstrated that socioeconomic determinants of health were not merely about us and them. Rich people compared to poor people, Australia compared to Sub-Saharan Africa. That health disparity could happen even when people earned a living wage and had access to complete universal healthcare, like those included in the Whitehall study.

Here in Australia, a country rich in resources with a largely socialised healthcare system, I can travel from my home in Sydney's Northern Beaches to the Blacktown region in Sydney's western suburbs and witness a 1.5-fold increase in people reporting high or very high psychological distress. It is no coincidence that I would also see nearly a four-fold increase in unemployment, a six-fold increase in the number of people on long-term unemployment benefits, a four-fold increase in the number of households receiving Centrelink rent assistance, and an eight-fold increase in the number of children growing up in low-income welfare-dependent families.[6] The comparison would become even starker if I flew to Brewarrina on the New South Wales–Queensland border, where just over 15 per cent of the population report high or very high psychological distress, nearly 17 per cent are unemployed, and two in every three children are growing up

in a low-income welfare-dependent family.[6] Even with access to medical services that are largely, for now at least, free at the point of care, the effect of social disadvantage is readily apparent.

If this is so apparent, you might ask, where is the action? You might ask more stridently given the most recent federal budget that announced, among other things, plans to make people under the age of thirty who become unemployed wait six months for income support.[7] Unemployment and financial hardship are consistently associated with psychological distress.[4,8–10] With Australians under the age of thirty having the greatest proportion of mental disorders[1] it is not hard to conclude that policies targeting younger Australians directly may have disastrous consequences.

The problem with action is simple. Like many public health problems mental ill health is associated with social disadvantage and social disadvantage is not experienced by the people in society who have the political and social power to do something about it.[11] Mental health in Australia experienced a brief moment in the sun when Julia Gillard was able to draw on her personal experience to garner the political will to do something.[12] However, in an all too common pattern, those days seem to be over. Public attention wanes when the realities of the actions required to effect real change become apparent.[11] The current government, it seems, has now turned its back on mental health and is focused on allegedly rampant public spending and the need for "austerity-like" measures.[13]

Austerity: the economic foundation for the end of equity

The most recent federal budget in Australia was a lesson in devaluing people, with deep spending cuts that will inevitably hit those sitting at the bottom of the socioeconomic ladder the hardest. The 2014 budget and the political rhetoric surrounding its release indicated that Australia's economic model will become one of austerity instead of stimulus. What does this mean for mental

health and mental health services in Australia? For inspiration we need only look to Europe.

Austerity, a word used often in political rhetoric, is an economic theory that seeks to reduce government debt by reducing government spending and labour costs, increasing taxes and shifting the burden of public services to the private sector. Dexter Whitfield from the University of Adelaide neatly sums it up in his report *Unmasking Austerity*: "The socialisation of losses and the privatisation of profits is the prime political and economic objective of austerity."[14]

It is perverse that the global financial crisis, a crisis that was largely brought about by corporations' unchecked profiteering, resulted in a political and economic movement that has placed the greatest burdens on the poor and the workers while supplying corporations with bailouts and welfare. It is even more perverse given the fact that austerity hasn't worked; in fact austerity in Europe has just deepened the financial crisis and increased government debt.[9,14] Europeans have experienced a reduction in services, an increase in unemployment, an increase in suboptimal employment, a contraction of the public service, a reduction in housing values, and a reduction in social welfare provision, all while corporations have experienced an increase in profits.[14] Austerity measures have led to an increase in poverty and a widening social inequality that not only threatens the health and mental health of the current population, but also has the very real potential to result in ill effects that will be seen far into the future.[4]

So, if austerity is such a monumental failure why is the current government pursuing it with such apparent relish? I believe the answer to this lies in ideology as opposed to economics. So-called neoliberal economic ideology values free trade, competition, consumer growth based on debt, tax cuts for the wealthy, deregulation, and privatisation of government services.[9,14] Is this starting to sound familiar? The last federal budget read as an homage to the neoliberal ideas of a market-driven society where

governments take a smaller role in favour of corporations. However, this ideology fails to provide adequate protection to society.[11] Indeed this ideology fails in almost all respects. At the root of the most recent global financial crisis was the idea that the market will "self-correct" and that markets free from the apparently toxic influence of government regulation are the best mechanisms for optimal outcomes.[9]

Mental health in times of austerity

While corporations were the cause of the global financial crisis it is the public in many countries who have been forced to carry the burden of an apparent solution.[4,9,14] It will come as no surprise then that one of the costs of austerity in Europe has been rising psychological distress and increases in suicide rates.[4,9] Greece, the United Kingdom and Italy all report excess suicides correlated with increasing financial hardship.[4,9]

However, the picture need not be so bleak. In some countries suicide rates have remained steady or even fallen in the face of the same patterns of rising unemployment. This better picture appears to correspond with the level of social protection governments offer their citizens. In Italy rising unemployment was only associated with increasing suicides in regions where there were low levels of social welfare.[4,9] Compare Sweden, a country with a strong social welfare system, to Spain, where investment in social protection is minimal, and you see a remarkable effect. In Sweden rising unemployment was actually associated with a drop in suicides and no increase in other health disparities.[4,9] In Spain, which spends roughly a quarter of what Sweden does on labour-market protection, unemployment and suicides follow the same distressing upward trend.[4,9]

It is a terrible false economy to think that disinvestment in people will save money. Mental ill health is an enormous financial burden. In the European Union mental ill health is estimated to cost 3–4 per cent of gross domestic product in lost productivity.[4]

In fact, investing in good mental health promotes economic growth by fostering a productive population.[4]

Good mental health in Australia: it's time to invest in people

So much has been written on what needs to be done in mental health in Australia. A quick Google search will reveal page after page of reports and interim reports, and reports on reports, all talking about what we should do, what we can do, what we *must* do. But where is the action? And importantly, where is the action on aspects that lie outside the purview of the health service?

The recent Australian mental health survey found that two out of three people who experienced mental ill health did not access healthcare services, yet of these people only a minority felt that they actually needed those services.[1] Could it be that focusing simply on investment in healthcare is an impoverished view of what needs to be done? Investment in health services is important – vitally important for people who access the services – but it is only part of the solution. Unfortunately it is the relatively easy part of the solution. Investment in health services is an easy sell for politicians, for the electorate, for clinicians. Although in mental health, a sector of healthcare that has suffered decades of under-investment, easy is a relative term. Mental healthcare services are in dire need of investment.

However, the issue with making healthcare investment the sole focus is this: people have a trust in medicine and health that has been nurtured over years of market-driven philosophy.[11] Take this medicine and you'll get better, use this device and your body will work better, access this health service and your health issue will go away. This thinking, though, is merely an extension of the cult of the individual.[11] The trust in healthcare is society's way of ensuring that the solution to any health problem lies with the individual and thus society is absolved from the responsibility to act collectively in a way that may make a difference.[11] A state-of-the-art mental health service will obviously provide many

people with the care they desperately need. However, focusing on healthcare at the expense of implementing policies to lessen the broader social determinants may burden people with ill health that could have been prevented in the first place. Creating a society that fosters and supports positive mental health is something we should all strive for, and healthcare services are only part of a much larger picture.

The World Health Organization states that policy action in areas other than healthcare can have a positive benefit on whole-of-population health, mental health included. Investment in public services can ameliorate the effects of inequity.[4] So many determinants of good mental health lie outside the remit of the healthcare system: for example, job security, social security, access to education, and provision of welfare. If Australia wants to avoid a European-like crisis then we need to take action now. The spending cuts proposed in the latest federal budget will do nothing except cause Australia to follow in Europe's footsteps.

We need to decide collectively as a society: do we care about mental health? And if we do care, we need to decide what we are going to do about it. Are we prepared to do the hard thing, to make the sacrifices that are necessary to ensure all Australians have the greatest chance of going through their lives in the best mental health possible? This means investing in people, not just in medical services. It means that those of us lucky enough to enjoy a high standard of living must commit to making the necessary sacrifices to ensure that this standard is shared with all Australians. I hope we do care, for the sake of the woman who sat in her living room staring at her children, struggling to shake off the feelings of despair, and for all the millions of Australians who are currently in the midst of their own personal struggles.

Author

Olivia Hibbitt is a medical writer at NPS MedicineWise where she produces content for health professionals and consumers on quality use of medicines

and medical tests, and other health topics. She is also completing a Masters in Public Health from the University of Sydney.

Endnotes

1. Tim Slade, Amy Johnston, Marie Teesson, et al., *The Mental Health of Australians 2: Report on the 2007 National Survey of Mental Health and Wellbeing*, Commonwealth of Australia, 2009, accessed at http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-m-mhaust2.

2. Joe Hockey, "The End of the Age of Entitlement," *The Age*, 19 April 2012, accessed at http://www.theage.com.au/national/the-end-of-the-age-of-entitlement-20120419-1x8vj.html.

3. Joe Hockey, "We Are a Nation of Lifters, Not Leaners," *Australian Financial Review*, 14 May 2014, accessed at http://www.afr.com/p/national/budget/joe_hockey_we_are_nation_of_lifters_emUX2Sg4Gm8S6T7L59KNvL.

4. World Health Organization, *Impact of Economic Crises on Mental Health*, 2011, accessed at http://www.euro.who.int/__data/assets/pdf_file/0008/134999/e94837.pdf.

5. M.G. Marmot, G.D. Smith, S. Stansfeld, et al., "Health Inequalities among British Civil Servants: The Whitehall II study," *The Lancet*, 1991: vol. 337, no. 8754, pp 1387–93.

6. Public Health Information Development Unit, "ML Single Maps – with PHAs: Chronic Conditions and Health Risk Factor Estimates Only," *Social Health Atlases of Australia: Medicare Locals*, University of Adelaide, 2014, accessed at http://www.adelaide.edu.au/phidu/maps-data/maps/.

7. Bridie Jabour, "Coalition's Welfare Changes Could Breach Human Rights, Inquiry Finds," *The Guardian*, 30 September 2014, accessed at http://www.theguardian.com/australia-news/2014/sep/30/coalition-welfare-reforms-could-breach-human-rights.

8. Martin Knapp, "Mental Health in an Age of Austerity," *Evidence-Based Mental Health*, August 2012: vol. 15, no. 3, pp 54–5.

9. Roberto De Vogli, "The Financial Crisis, Health and Health Inequities in

Europe: The Need for Regulations, Redistribution and Social Protection," *International Journal for Equity in Health*, July 2014: vol. 13:58.

10. Andrew Mackinnon, Anthony F. Jorm and Ian B. Hickie, "A National Depression Index for Australia," *Medical Journal of Australia*, 2004: vol. 181, no. 7, pp S52–6.

11. Dan E. Beauchamp, "Public Health as Social Justice," in Martin T. Donohoe, ed, *Public Health and Social Justice*, first edition, Wiley, Hoboken, 2012, pp 11–22.

12. Mental Health Council of Australia. "Gillard Government Delivers on Mental Health Commitments," 10 May 2011, http://mhaustralia.org/sites/default/files/imported/component/rsfiles/media-releases/2011/Budget_delivers_on_mental_health_committments.pdf.

13. Jim Chalmers, "Tony Abbott's Austerity-like Measures Will Hit Poorer Communities the Hardest," *The Guardian*, 23 January 2014, accessed at http://www.theguardian.com/commentisfree/2014/jan/23/tony-abbotts-austerity-like-measures-will-hit-poorer-communities-the-hardest.

14. Dexter Whitfield, *Unmasking Austerity: Lessons for Australia*, University of Adelaide, 2014, accessed at http://www.adelaide.edu.au/wiser/docs/WISeR-ESSU_UnmaskingAusterity2014.pdf.

Schizophrenia: a dialogue on progress

Sandy Jeffs and Margaret Leggatt

Has schizophrenia as a label, an illness, a diagnosis, or even a concept outlived its usefulness? Have we managed to destigmatise it? Or do we no longer mention it because in the public mind it continues to be the most feared and reviled of mental illnesses? This is a dialogue between Sandy, who has lived with schizophrenia for thirty-eight years, and Margie, a mental health advocate since 1978.

Sandy

If you were condemned to suffer a mental illness, which one would you choose? If you chose depression you would have a condition shared by a number of high-profile celebrities, politicians and sports stars, many of whom have been encouraged by Beyondblue to talk publicly about their struggle with and recovery from "the black dog." This PR juggernaut has succeeded in drawing so much support as to make depression the mental illness of choice. Now celebrities are coming out with other conditions, like bipolar disorder. It is okay now to speak publicly about mental illness – and this is good, because it shows that mental illness does not

necessarily prevent people from exercising talents in many fields. But only if it is depression or bipolar; schizophrenia continues to be associated with violence and mass murder.

Two recent examples of mass murder in which the perpetrators were immediately associated with schizophrenia were the well-publicised cases of Anders Breivik in Norway in 2011, who murdered seventy-seven people, and James Holmes in Denver in 2012, who shot seventy people in a cinema, killing twelve.

The Breivik case highlights the psychiatry profession's problem with credibility. One team of court-appointed psychiatrists diagnosed Breivik with paranoid schizophrenia, but another team of psychiatrists, also appointed by the court, disputed this diagnosis, saying he was not psychotic but had a narcissistic personality disorder. The court found Breivik to be bad, not mad. Holmes, the Denver killer, was supposedly seeing a psychiatrist who specialises in schizophrenia, so the media and the public inferred that he must have schizophrenia. On the web, people suddenly became amateur psychiatrists, diagnosing Holmes with paranoid schizophrenia on the strength of media reports.

Whenever I see a report in the news of a rampaging killer, or an assassination, or a person acting irrationally in a public place and causing mayhem, I make a silent prayer: *please don't let this person have a diagnosis of schizophrenia*. I don't want to feel ashamed again of this label I must also wear.

The diagnosis and nomenclature of schizophrenia have been controversial since 1911, when Swiss psychiatrist Eugen Bleuler brought the term into the psychiatric lexicon. Bleuler's definition meant "split mind" but lay people misinterpreted this as "split personality." This idea of a person being able to shift between two personae, good and evil, had taken on wide cultural significance since Robert Louis Stevenson's 1886 novella *The Strange Case of Dr Jekyll and Mr Hyde*. The notion had created a fear, in the collective consciousness, of what those labelled "schizophrenic" might be capable of, like morphing into the monstrous Mr Hyde.

Someone once asked me, when she found out I had schizophrenia, "Who are you when you are not Sandy?"

Margie and I became friends through our association with the Schizophrenia Fellowship of Victoria (now the Mental Illness Fellowship), a self-help and advocacy organisation for people affected by schizophrenia, and their families. Since the late 1970s, Margie and I have shared a desire to make life better for people diagnosed with schizophrenia, and their family and friends who care for them. Yet, for all the thirty years we have worked together in our related spheres of interest and concern, we now question what real progress has been made.

Is there any less stigma attached to schizophrenia than there used to be? If so, why is there perhaps an even greater reluctance to use the S word? Why am I hearing the same stories from people diagnosed with schizophrenia that I heard thirty years ago? Why does the concept ignite such fierce debate – about exactly what constitutes the condition, or even, now, whether such a condition exists? Has schizophrenia become the "abandoned illness," as a report by the Schizophrenia Commission in the United Kingdom declared in 2012?

Margie

And why am I hearing the same stories from family carers – about how they are ignored, not respected, and not helped to cope with difficult situations? Why are they not listened to, when they have valuable information to give? Why are there long delays in getting appropriate help when someone is becoming mentally unwell?

What is schizophrenia?

Sandy

It was 1976 and I was twenty-three. I was sitting in front of a psychiatrist who told me I had "schizophrenia." This sounds serious, I thought, but what is it? I sat there, perplexed by psychotic

confusion – terrorised by persistent voices telling me I was evil; caught up in bizarre delusions. I was preoccupied with visitations by the Virgin Mary and a hag who kept appearing in my mirror. The outer world menaced and bombarded my inner world.

Sometimes I seemed to be able to do at least ordinary things, like go to the shop to buy bread and milk, meet friends for a meal, see a film or play tennis. At other times I was too overwhelmed, or too distracted, by the ridicule and abuse of persecuting voices, which made me feel worthless, useless. They told me my friends wanted to harm me, so I withdrew from those friendships. Even the radio was giving me cosmic messages – that I had the power to contaminate people with the evil emanating from my body, and that my thoughts were being broadcast to the world. I was terribly alarmed that strangers could read my festering mind. I was admitted many times to a psychiatric hospital.

When I started hearing the voices of my madness, clinicians saw them as random and rambling voices that had no intrinsic meaning, caused by a mind swimming in unbalanced chemicals. I don't recall any psychiatrist asking what my voices were saying to me. All the vitriol and persecution of my voices, all their references to me as a *slut*, *trollop*, *Satan's whore* and *bitch*, were simply to be medicated out of existence. I now believe they were telling me something. Their repeated references to me as a slut and whore surely hark back to myself as a thirteen-year-old girl dreadfully shamed by the man who raped her.

The certainty of my diagnosis of schizophrenia has wavered over the years because one psychiatrist has thought that I may in fact have "schizoaffective disorder," a condition that encompasses mood shifts common to bipolar mood disorder as well as psychotic symptoms common to schizophrenia.

Assuming I do have schizophrenia, what was its cause?

Back in the 1970s, schizophrenia was seen to be caused by dysfunctional parenting; these days the spectre of childhood trauma lurks also.

I am the victim of a traumatic childhood. My mother was an alcoholic and alcohol played a big part in our unhappy family. My father was a wife-beater. This made for a deeply distressing environment in which to grow up. I felt unloved and unlovable. I have two siblings who both experienced the family violence and their own trauma. Why didn't they fall into a mental illness? What was it in me that tipped me over the edge? Did my lesbianism contribute to the mental illness; was it a personal weakness? Was I too sensitive to the world? Was my brain overrun by unbalanced chemicals? And what about the sexual abuse?

Was it an incremental accumulation of all these traumas that made me vulnerable to developing schizophrenia?

Margie

I have worked with countless families with children who have schizophrenia where there is no history of family trauma or childhood sexual abuse. Parents are coping with schizophrenia under the most difficult of circumstances. Often they feel they are not coping; they cannot understand what it is that they are dealing with. They are worried, frightened, desperate and totally bewildered by the inexplicable changes in the behaviour of their sons and daughters; they become very stressed, distressed, isolated, and physically and emotionally unwell themselves in the process.

Evidence has also been accumulating for theories that schizophrenia has origins in brain dysfunction. These theories suggest that the *acute* symptoms – distorted perceptions, like hallucinatory voices and visions; distorted thoughts, like feeling persecuted or spied on, or believing you have special powers; and disordered emotions, like feeling evil, worthless, unloved – result from chemical imbalances in the brain stem. Medications have been discovered that can treat these acute symptoms by removing them, or at least subduing their intensity.

The thinking on *chronic* symptoms is that they are caused by dysfunction in the prefrontal lobes of the brain – the area

in humans for "higher learning." Dysfunction in the prefrontal lobes leads to personal disorganisation: diminished grasp of abstract ideas (concrete thinking), inability to plan realistically (poor recent memory, loss of the sense of the future), lack of initiative, lack of motivation, reduced conversational ability (lack of expression and spontaneity), indifference and apathy, socially inappropriate behaviour, poor problem-solving, and an inability to integrate thoughts with appropriate emotions. Problems with capacities for focus and attention indicate possible dysfunction in the hippocampus. The chronic symptoms are not helped much by medication.

Nowadays the generally accepted explanation for schizophrenia goes something like this: biological vulnerability plus environmental stressors can result in the development of mental illnesses such as schizophrenia. Mental illnesses are the product of continual interactions between brain dysfunctions and emotional and social phenomena experienced as stressful and traumatic. In other words, mental illness is not caused by either nature *or* nurture, but by their interaction at critical periods of psychic development.

Our fight to destigmatise schizophrenia

Sandy

Over the past three decades the "medical model" of biological causes – chemical imbalances in the brain – has become more widely accepted, and I used to find it comforting. It didn't blame me, my parents or my circumstances for my schizophrenia. I was mad, not bad. I could hope that I might be helped by medication or, even more optimistically, that my condition was treatable and even curable.

This became the narrative, the story I told myself in order to understand and cope with my wayward mind and incomprehensible behaviour.

Over twenty years ago I started speaking publicly about my schizophrenia. Other mad people like me, burdened by misunderstood diagnoses, stepped out of the mythology to give schizophrenia a human face. I found myself in front of school kids, university students and community groups, telling my story. I was featured in print media, and on radio and television.

If people could only understand that schizophrenia was an illness, we believed, the stigma and associated rejection and isolation would end.

Margie

We determined together to debunk the myths: schizophrenia is not split personality, as per Dr Jekyll; the illness, if detected and treated early, can be ameliorated. Letters to the *Age* railed against the common, inaccurate use of the word, as in, "I feel a bit schizophrenic today because I can't make up my mind" or "the member of the opposition is schizophrenic – on the one hand he says this, on the other he says that."

But different problems with public perceptions began to emerge. There were perplexing cartoons: people with schizophrenia were drawn as grotesque caricatures, or menacing, or in dark shadows (mysterious, and not open to communication). Media descriptions were designed to shock: "Rampage man on God's mission – man fails to take prescribed drugs"; "Feral psychotics will soon be roaming Melbourne's streets" (on the closure of mental hospitals); "Cease-fire – 8 people shot dead by police this year" (on the inability of police to deal with the psychotic).

Julian Knight, the man who killed seven people and injured nineteen during a shooting spree in Clifton Hill, Victoria, in what became known as "the Hoddle Street massacre," did not have a mental illness. Yet the media used expressions like "crazy gunman," "insane attack" and "act of madness" when describing the event. At the time of the Port Arthur massacre – the mass

shooting by Martin Bryant in Tasmania – the media asked, "Does this young man have schizophrenia?"

On the rare occasion when someone with a mental illness did commit a crime, headlines were unrelenting: "Schizo Knifed Mum," "A Smiling Assassin," "Murder-suicide Man Refused Medication."

Labelling people as crazy or mad, implying mental illness, when no mental illness was present, was bad enough. But when someone with schizophrenia did commit a serious crime, all our efforts at getting the true understanding of schizophrenia out into the open were obliterated. Our statements that only a small proportion of people with schizophrenia are violent, or that the vast majority of violent crimes are committed by people who don't have schizophrenia, seemed feeble against the blaring insistence of media reportage.

Sandy

It is pretty devastating to look back at our long struggle to destigmatise mental illness and particularly schizophrenia, to find that bringing it out into the open, speaking about it, may simply have reinforced fears about the nature of schizophrenia rather than fostered a more accurate understanding of it.

Margie

So what needs to be done? What is a way forward? Perhaps a strategy for future "anti-stigma" campaigns is to focus strongly on the abilities and competencies of people with illnesses like schizophrenia.

And you, Sandy, are a superb example. During our long association, I have been aware of your admissions to hospital when the symptoms became overwhelming; I have admired your unremitting capacity to get going when you wake up every morning and have to come to terms with suicidal thoughts. You have a diabolical sense of humour and can make me laugh more than anyone else I know.

Although you suffer great distress from hallucinatory voices, you don't exhibit the chronic symptoms of schizophrenia. Every time you call yourself a madwoman, I want to loudly contradict you. Outwardly, to me, you are anything but mad. You are highly intelligent, well-read, perceptive and great fun. You are an accomplished author of a wonderful book on your experiences with mental illness and the psychiatric system; you have published volumes of poetry; you continue to lecture frequently at conferences, to students, and to community groups. And in spite of your constant struggle with schizophrenia, you are not bitter or angry.

However, as you have said, schizophrenia is as individuated as the minds it touches.

Sandy

Schizophrenia cannot be pigeonholed into one homogenised phenomenon. Each of us diagnosed with it experiences voices, hallucinations and delusions differently. The repertoire of the mad mind is breathtakingly broad, a product of the imagination, which is limitless.

Margie

This complexity is possibly one cause of people's confusion about schizophrenia; and one of the major reasons why overcoming the stigma associated with schizophrenia has so far defeated us.

The story of "Michael," who has one form of schizophrenia, provides an example. Listen to his mother, as we can only learn about his illness from her, because he does not see himself as mentally ill:

> When Michael is becoming unwell, I observe confused, irrational thinking, paranoia – he believes that people are "out to get him." He believes the television is talking to him, and his phone is bugged. But he is adept at holding himself

together and appearing rational and in control when he is under threat of hospitalisation.

Michael has what is called "no insight" – an unwillingness to admit he has a mental illness. This is also referred to as "denial of illness," and is perhaps the most troubling aspect of some forms of schizophrenia.

Recent studies link poor insight to some dysfunction in the frontal lobe. Although the notion of brain dysfunction may sound untreatable, it is actually grounds for renewed hope. Recent work on brain plasticity shows that rehabilitation is possible following many types of brain damage. Rehabilitation specialists are trained in cognitive remediation – the remedying of deficits in the capacity of knowing. Michael has never been offered cognitive remediation to help him develop awareness of his illness and learn new skills for active participation in his own treatment. Michael's abilities – and he is a very intelligent young man – are not being developed because our system is not helping him in a way that could lead to his recovery.

Trying to reconcile the family's story with that of the unwell patient creates distressing dilemmas for mental health staff. (Ever heard the expression "house devil, street angel"? Michael's form of schizophrenia is like that, which is perhaps why the story of Dr Jekyll becomes confused with schizophrenia.)

But something is seriously wrong with our system if we wait until a disaster occurs before we insist someone receives treatment. Michael hates taking medication, which has bad side effects; and, after all, he does not feel ill. For him, being forced into medical treatment when he doesn't see himself as sick is an injustice, and a denial of his human rights, his dignity. Yet there is no doubt that he is a very mentally unwell young man. The anxiety and stress experienced by his family and his girlfriend (who also has schizophrenia; he has no other friends) becomes intolerable.

A similar situation in Sydney recently ended in appalling tragedy, with the murder by Anthony Waterlow of his father and sister in 2009. The *Good Weekend* ran an article on the murders, "The Killer Inside," with the introduction "Mental health protocols failed a family who, despite their fear, tried to support their loved one – a man whose final murderous act changed lives forever."[1]

Most notable in the stories of Michael and Anthony was their capacity to persuade mental health staff that they did not need, nor did they wish to take, medication. Even when staff know that medication will help, people cannot be forced to take it if they do not want to; it can only be made compulsory if they are deemed a danger to themselves or others.

But people like Michael and Anthony are not likely to tell you that they may harm someone. You can only discover this by talking to others who know them, and mental health staff often don't do this. Anthony's family were aware of how unwell he was, and close friends were also saying that Anthony would harm someone. He told them voices said his father and sister were conspiring against him. Ultimately he felt so threatened that he killed them. After being arrested and tried, Anthony was found not guilty by reason of mental illness.

Should people who are unable to recognise their mental incapacity be allowed to deteriorate mentally in the name of preserving their choice to decline medical treatment? In so doing, they often infringe the rights of others, particularly those closest to them who are trying to help them.

I know of situations where people have received treatment against their will after committing crimes (and some of these crimes could have been prevented had they received early intervention treatment). Their illnesses are now under control and they are leading useful lives in the community. So, although people with schizophrenia may have no understanding at the time that they are very unstable, they can be turned around.

Sadly, tragic stories like Anthony's colour perceptions of all those with schizophrenia, the majority of whom are not violent.

Medicalising schizophrenia: the good and the bad

Margie

The discovery of antipsychotic medications in the mid 1950s allowed people to leave hospital care when the acute episode of the illness had subsided. In later years, further advances were made in the development of long-acting antipsychotic medication.

In a survey in 1985, carried out by the Schizophrenia Fellowship of Victoria, of 191 people with diagnosed schizophrenia, half claimed to have no problems with their medication, which had allowed a "return to normal."[2]

But the other half complained of a range of side effects. These included Parkinsonian-type tremors, stiff walking, slurred speech, blurred vision, thirstiness and a dry mouth, eyes rolling back or becoming glazed, and having to pace up and down to relieve restlessness. Another major set of responses described a constant sensation of over-sedation, lethargy, an inability to get up in the morning, feelings of physical weakness, and a lack of stamina.

Sandy

Imagine feeling sedated to exhaustion and that your head is stuffed with cotton wool; your thoughts are slow and jumbled, you feel numb and unresponsive, your feet feel as though they are dragging a ball. Imagine being made to shuffle like a decrepit person, or your libido is dead and your mouth is so dry it's like sandpaper, or your hands tremble and constipation clogs you. This is how it feels for many when taking antipsychotic medication.

Margie

The survey of these 191 young adults with schizophrenia also asked them to describe just what their lives in the community

were like. The sample reported that disorders of emotion (depression and anxiety mainly) were still very troublesome; mental and psychological changes, and interpersonal behavioural problems interfered with their capacity to form close relationships; they felt the need to withdraw socially, which led to extreme loneliness. The majority had found it impossible to return to the workforce or to become involved with further education. Most were living at home with ageing parents, while others continually and fruitlessly sought alternative accommodation.

Most respondents experienced financial insecurity. They received the invalid pension or sickness benefit and were heavily dependent on and subsidised by their family carers. They did not participate in domestic, social or recreational activities to any significant extent. This was in spite of the benefits of medications.

Sandy

A recent government report, *People Living with Psychotic Illness 2010: Report on the Second Australian National Survey*, states rather glibly that the newer medications better control delusions and hallucinations, and people are hospitalised less frequently than when the first survey was conducted in 1998.[3] But if this were true, why are the remainder of the findings so depressing? Far too many still experience unemployment, are on government benefits, are socially isolated and have to rely on families – the stories are the same as in earlier reports. For most, it is not so much the illness that bothers them as the unhappy social circumstances in which they are placed.

The earlier antipsychotic drugs were crude but the newer medications, heralded as wonder drugs to transform the lives of people with schizophrenia, have failed to live up to the hype. In my experience, what they do is flatten the illness into a chronic, low-level ongoing condition; they may reduce the florid blowouts but leave us with lethargy, withdrawal and social incapacity.

These newer medications result in higher than average rates of diabetes and obesity as well as other physical health issues such as asthma, circulatory conditions and respiratory problems. People living with psychosis are often heavy smokers and high users of alcohol and illicit drugs – most likely attributable to their ongoing difficulties in finding meaningful social roles. It is no surprise that those of us with schizophrenia die about twenty years younger on average than the general population.[4]

And, of course, the medicines are not curing schizophrenia.

Sadly, nothing much has changed in the lives of people living with a psychotic illness, since the first national report in 1998, or even since the report done by the Schizophrenia Fellowship in 1985.

And now, in the postmodern world of today

Sandy

In the 1960s and 1970s some theorists romanticised people who live with schizophrenia as being on an inner spiritual journey, finding meaning where the rest of society never could; or that this kind of madness was a sane response to a mad, rampantly capitalistic world. It was, for us "schizophrenics," at least a richer kind of identity than one defined solely by our affliction.

Postmodern intellectuals are again raising the notion of schizophrenia as a metaphor for the fragmentation of culture – the struggle of the creative mad genius against an uncaring, ignorant society. And once-subordinate marginalised groups are again challenging dominant discourses. The mad are not only challenging the discourse of psychiatry but also seeking to have more equal say in their treatment. An example is the rise of the Hearing Voices Network and the Paranoia Network, whose members speak of themselves as "voice-hearers," or "people living with unusual and compelling beliefs," and prefer their experiences to be seen as "mental distress." This is preferable to being classified

by that most stigmatising of psychiatric labels – "schizophrenia." Part of this new approach is not to medicate the voices or the paranoid thoughts away, but to engage in a therapeutic relationship that helps those experiencing them to gain control over, and live more tolerably with these terrors.

My sense is that the rise of activist consumer organisations such as these is a response to psychiatry's fierce promulgation of the medical model and over-reliance on medications. Many of us with conditions of "mental distress" would like to see mainstream practitioners consider more holistic approaches, and would like more opportunity to be partners in recovery rather than simply submitting to how others define and therefore treat us.

And what of the families?

Margie

In 1987 another survey carried out by the Schizophrenia Fellowship of Victoria asked 273 family members what their lives were like, now that they were caring for a family member with schizophrenia.[5]

They reported that medical staff did not give them information about the illness, let alone techniques for managing difficult behaviours. Obtaining help when it was needed was always difficult, leading to inordinate delays and often disaster. Emotional relationships with their unwell relative had markedly deteriorated. Attempts by the young person to leave home were frustrated by the lack of suitable supported accommodation facilities; most were unemployed. Many families struggled to meet the added financial burden of an adult relative. The caring role had also severely limited their social lives. And many reported that caring for their mentally ill relative had caused their own serious physical and emotional health problems.

In 2009 a survey by the Mental Health Council of Australia, *Adversity to Advocacy*, revealed fifteen key issues affecting mental

health carers.[6] I felt angry and frustrated that the issues were the same as those found by the Schizophrenia Fellowship in 1987. The plethora of government reports, policies and strategies for mental health reform had not improved the experiences of mental health carers.

Social research carried out over the last thirty years in the United Kingdom and the United States has shown that astonishingly positive results can be achieved by bringing together those with a mental illness, family carers and clinicians to develop plans of action mutually agreed by all parties.

This working together continues over an extended period until effective communication and problem-solving techniques have been learned. The research results reveal a reduction in relapse rates through the earlier detection of symptoms and earlier treatment, a decrease in hospital admissions, better adherence to medication, and better co-ordination of treatment and care. There are trends towards improved social functioning, increased employment and involvement in community activities, and reduction in the burden and stress experienced by family carers.

Some of the studies have also reported significant decreases in the cost of treating the mental illness, and therefore significant savings for the mental health system.[7]

It is surprising, then, that these findings from social research are not generally well known, let alone implemented into routine mental health practice.

Sandy, somewhat pessimistically

So even though mental health is discussed more openly and widely than when we began the work of reform, and even though there are some positive research findings, the situation for many with the diagnosis of schizophrenia remains enigmatic. And as other mental health conditions become more visible, schizophrenia has retreated further into the shadows. One has to be

brave to say, "I have schizophrenia." The label remains the one to fear the most, and the stigma is as powerful as ever.

What if the diagnosis of schizophrenia were to be dismissed and the label removed from the lexicon? How would I explain what has happened to me for these last thirty-eight years?

Some names have been proposed as alternatives to schizophrenia: for example, salience syndrome, psychosis susceptibility syndrome, psychotic spectrum disorder, and dysfunctional perception syndrome. Would changing the name of schizophrenia make a real difference to the lives of those who carry its label? The Japanese have adopted a new name for schizophrenia and, by all accounts, it has made a difference to the preparedness of people to seek treatment, because it has less stigma.

But changing the label doesn't change the behaviour associated with a psychotic illness – the bizarre and perplexing behaviour that makes people call us loonies, crazy, cut snakes, idiots. Will stigma only cease when a cure is found for schizophrenia and those who suffer it no longer do "mad" things in the public gaze?

Until a cure is found, or more effective medications are developed with fewer awful side effects, or society embraces people with "mental distress" as just one more different kind of human being equally deserving of respect and compassion, I cannot see us escaping our mind-prisons, or the constant struggle of living with this cruel monster of a diagnosis.

Margie, cautiously optimistic

We need to revive our efforts to bring schizophrenia out into the open. We need to do it with different tactics and renewed energy. We need to push for the improvements that the positive social research results have demonstrated: include families in treatment and care, help people return to work or study, provide appropriate accommodation – all aspects of meaningful living that are not adequately taken into account in either the

intellectual/cultural metaphor or the narrow medical model. With these changes, the illness could become much more tolerable for both sufferers and carers.

Sandy

But then, Margie does not have to fight daily with the monster.

Authors

Sandy Jeffs is a poet who has lived with schizophrenia since 1976. She has been a public face for this often misunderstood condition for many years. *Margaret Leggatt* is a sociologist and has been a mental health advocate since 1978. She has had a special interest in the needs of family carers, and has fought for many years to have families included in the treatment and care of their unwell family member.

Endnotes

1. Pamela Burton, "The Killer Inside," *Good Weekend*, 22 October 2012, accessed at http://www.smh.com.au/lifestyle/the-killer-inside-20121022-27lqd.html.
2. Estelle Carey and Margaret Leggatt, *Profile on Schizophrenia: The Consumer Perspective*, Schizophrenia Fellowship of Victoria, Inc., 1985.
3. Commonwealth of Australia, *People Living with Psychotic Illness 2010: Report on the Second Australian National Survey*, November 2011, accessed at http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-p-psych10.
4. Schizophrenia Commission, *The Abandoned Illness: A Report by the Schizophrenia Commission*, November 2012, accessed at http://www.rethink.org/about-us/the-schizophrenia-commission.
5. Estelle Carey and Margaret Leggatt, *Coping with Schizophrenia: The Relatives' Perspective*, Schizophrenia Fellowship of Victoria Inc., 1987.
6. Mental Health Council of Australia, *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*, October 2009, accessed at http://mhaustralia.org/publication/adversity-advocacy-lives-mental-health-carers-october-2009.

7. William R. McFarlane, Bruce Link, Robert Dushay, et al., "Psychoeducational Multiple Family Groups: Four-Year Relapse Outcome in Schizophrenia," *Family Process*, June 1995: vol. 34, no. 2, pp 127–44.

A history of angel suits

Stephen Wright

Working with adults who have experienced violence as children often involves the invention of a language to describe childhood states. It is a language both transgressive and yet as wearable as a second skin, which speaks to a person's childhood in new ways.

In the crevices of my therapeutic work with those who have experienced childhood trauma and abuse I would sometimes remember Philip Larkin's poem "This Be the Verse," which begins "They fuck you up, your mum and dad." As I finished a set of case notes one morning, I realised that it was actually a poem addressed to children. I imagined it included in a children's poetry anthology somewhere between Robert Louis Stevenson and Michael Leunig. Larkin's poem has a ruthlessness about it that an adult might view as despair but children would claim with delight, a ruthlessness distinguished by its lack of lies and fantasy. Children, in fact, usually have little time for either.

The politics of trauma – of what it means to struggle into identity, to carry childhood and the world and its baleful interiors into that weird shifting space called adulthood and its engineered responsibilities – is the politics of how trauma is hidden, or redirected, cathected with the consumer paradise or fused with cyberspace.

But if we make some kind of movement in the direction of being able to bear the unbearable, and think about what that is, we might be heading towards the possibility of some kind of authentic conversation about what it means to inhabit a fragile, ungainly, diseased and unpredictable, politically disruptive and impermanent life in the cyber-age of violence, surveillance and control.

And if we are not gathering that understanding of how violence works and where it is hidden and what forms it has taken, then how can we know how to live?

What is sometimes called "mental health" is too easy to locate inside someone, as though it were a characteristic he or she possesses or has taken on, like putting on a coat. But those who have thought about their work with people characterised as "mentally ill," or read deeply into the history of aetiologies, know that what we now call "trauma" is ineluctably linked to what used to be called "insanity."

But traumatised people didn't just have an accident, or find themselves in the wrong place at a very wrong time. Trauma is not a random event, even though to the observer the temptation is to collude with the idea that it is. But neither is it preordained, as the traumatised can come to believe, as though they are condemned to live under a dark star that tracks their every thought and action.

•

For Australians, trauma is coded into every aspect of historical life. When I arrived in Australia as an eleven-year-old the emotions I frequently encountered did not correspond to any that I had experienced before. For me, Australia was not just a place, a landscape that seemed to be plunged into a deep and silent reverie conducted in a language of which the white inhabitants knew nothing, but also a state of mind. It was as if I had not just suddenly encountered the mind of another but was actually existing within the field of thought of that mind, an unconscious thought of unimaginable weight and density.

The pressure of historical amnesia in Australian life is very great. When the reality of Australia's hidden life bursts into public awareness propelled by forces we have long ignored, a tear is created in our amnesiac carapace that can never be fully repaired. This happened with the reports on the Stolen Generations, and is happening now with the Royal Commission into Institutional Responses to Child Sexual Abuse. It is true that Australian amnesia is partly a product of our institutions and regimes of normative control, but it is also a deliberate act, in that it can only be maintained through incessant labour even if we are largely ignorant of the energy we expend to maintain the work of forgetfulness.

Of course amnesia cuts two ways. It is a product of the knowledge or experience of catastrophe as well as a way of re-enacting catastrophe. Traumatised people can sometimes re-enact parts of their experience as a way of convincing themselves that it really happened.

To have the environment of one's childhood utterly obliterated is now a commonplace event. We have become people with nothing to go back to. All that we can inhabit of the past is memory and it is not surprising that waves of nostalgia frequently wash through modern life. It is as though we are immersed in the debris of the past, as if our past had been completely destroyed by an event of unstoppable force and magnitude – an event without pity that has ransacked our lives and stopped our mouths so that we are no longer able to describe what is happening to us, thrown back as we are into fragmented sites of memory through which we shuffle, picking at the wreckage.

The forces that wreaked such devastation on Aboriginal Australia and on the children so brutally abused in government and religious institutions are still at work among and within us. It is a grievous mistake to consign that destruction to events and attitudes that no longer exist. Not only are they still alive and more virulent than ever – playing out in the ecological devastation of the planet and its reduction to a husk to be mined and plundered

until it is dead – but they have become embodied in ways that our language now struggles to encompass.

And this embodiment is a kind of second skin in which we are enclosed – a skin that both compensates and was responsible for the primary skin's failure to contain, nurture and protect us. It is the contiguous surface that both connects us to the world and governs our interior shape.

I once wrote an essay on climate change in which I concluded that the reason we are so terrible at looking after the planet is that we are terrible at looking after each other. And while I still think this is true, perhaps in more ways than I knew at the time, this failure to care is also a mirroring of something, a splitting in ourselves that is perhaps an attempt to bridge a rift in us that is almost irreparable. It is like having two narratives running simultaneously, as if voices were speaking different words from the speakers of a stereo, each parallel voice plotting a different story that has curious and puzzling connections with the other – divergent and yet always about to effect an intimate recognition.

One voice is a kind of twining of threads, each a harvested echo of things that once gave us a private hope: the lyrics of songs, a book that once read us to sleep, an unexpected phone call, headlights at night, a window, a favourite pair of jeans. And the other voice is shaped by whatever your mind brings along to stave off the panic induced by the practices of political violence and cruelty that are now so common, a voice that is sometimes a little occult, as if we had a shaman living inside us muttering incantations that have a perfect logic only in dreams, dreams that we look to as oracles.

When confronted with Australia's violent histories, we can find ourselves immobilised by a paralysis that can be labelled apathy, as if we didn't care, when perhaps it is the case that we care too much. It can be unbearable to want to care and yet feel that you can't or don't know how to, or that to care is meaningless. We can sometimes feel like slaves whose effect on the phenomenal

world is always negligible, as if we are continually acted upon in a world where the only context for thinking is within the arbitrary and capricious use of sovereign power.

In other words, when those labelled "mentally ill" are confronted by monolithic terms like "depression" there can often be something transgressive taking place, gouging away at the heart of their lives. Depression isn't depression all the way down. Depression is the cement plug on top of a proliferation of other things, a concrete surface that itself resists description because description of depression can be both the destruction of depression and the revealing of a multitude of anxieties, themselves in need of redescription. In depression there's a lot of misreading and misrecognition, and in that sense it's possible that Australians are a depressed people.

•

I wrote that essay on climate change sitting in the living room of a farmhouse where I had just moved in. It was winter and a driving icy wind cutting up the valley from the south carried an extraordinary sleety rain. The house was then unheated and the room where I was sitting contained only a few pieces of furniture and several stacks of cardboard boxes that held my books.

When looking for a house to live in, one often begins to seek signs or omens, as if the house in which we are to dream and love were waiting for us and would speak in recognition. One of the people I worked with each week, distressed by repeated nightmares, asked me if I thought that houses could hold memories in their walls of the previous inhabitants, which could become intrusions in the mind of another. And in fact I think that when one enters an empty house the thousand tiny marks of the previous occupants are always registered somewhere in the mind; the scratches by the door, the old picture hooks, the odd pattern of nail holes in the kitchen wall, the newly cleaned stove and so on conjure up the ghosts of ghosts. They are the faded evidence of conspiracies and dreams and plottings about love. Children often

leave the most indelible marks, as if a house becomes bruised in the act of embracing them, as though that is what love does – leaves scars and marks of healed wounds.

It was during the period when I was moving house that I first began to work with those survivors who had experienced so much violence at the hands of priests and others professing to do the work of God. It was as though a brigade of petty demons, chosen for their malice and their addiction to torture, had emerged from the city of Pandaemonium and adopted the guise of priests and evangelists; not in order to pass unnoticed, but to derive a greater pleasure from their practices of violation, as the disguise itself became part of the apparatus of torture.

And perhaps it would be easier for those of us who listen to the stories of the raped and abused if this were true. Presumably there are tried and true methods of exterminating demons that we could then use, some magical words of power that would cause the heads of the abusers to explode or reduce their bones to ashes. The reality of course is more destabilising and crazy-making.

And sometimes in my work I have had occasion to speak with those who have assaulted children. To have a conversation with someone whose brutality to children seems unfathomable is to enter an experience that seems both otherworldly and yet irrevocably rooted in the most toxic effluent. Such individuals can appear pious, friendly, even humble and sincere. And yet one can begin to feel haunted in a strange, dead way, as though something were invisibly and perpetually leaching out of them, as if the price of their brittle disguise were a continued tax in blood diamonds being secretly paid in some dim and wretched hole lit by shadows as terrifying as those of preying insects.

One can leave a relatively banal conversation feeling as disturbed as if one had just overcome a bout of seasickness, and yet were confused as to where the disturbance was, or what was responsible for it.

Of course it is true that we all tend to speak each other's unspoken thoughts, even in the most ordinary of interactions. A mind is not a closed container, even though we are capable of carrying out containing functions for each other, holding and processing each other's anxieties, for example. And wherever the mind is, it tends to be both porous and as sensitive as velcro or the hairs on the legs of bees to which pollen adheres.

But when someone does not possess a mind as such, no thinking apparatus, but only the surface of a locked cognition behind which is a kind of relentlessly sucking vacuum, the experience can be like stepping out into a void that appears to have a gravity of its own, which can drag one into a state of diffuse and acquiescent terror.

•

The history of violence in Australia is often a history of cruelty towards children and their mothers. This cruelty is an attempt to make them disappear, as though we cannot bear to see children whose condition is a product of the rigid attitudes and practices Australians have often held so dear: the child abused in the suburban family; the mother who gave birth without a family; both punished for the sins of others and their own marginal condition.

It is a common experience when one is working with difficult children – children who confound the expectations of adults and seem to be inhabiting their own secret labyrinths – to seek magical solutions, to try to sound out that one huge jazz note that could bring the walls around a child crashing down, admitting him or her to our benign adult presence. And such a futile and grandiose search is perhaps what so often leads adults to solutions that involve regimes and medications, as though a child who is hard to reach were blown by a wind of sickness, or engaged in a tribal warfare with the adult world.

And in the face of children's guerilla warfare, it is not unusual for the magical solutions of adults – which are not solutions at all, but manic and paranoid defences – to become reified

and truncated philosophies, cultish states of mind in which everything must fit or be cut away, split off or annihilated.

But buried in our misreadings of children, and our subsequent building of prisons and fortifications and master plans for them, is the secret fear that we are not good enough to be redeemed for our failures to remake the world in our own image.

This was clearly the case with those adults I worked with who had experienced institutional abuse as children, an abuse that was so brutal and savage as to qualify as demonic. They were children in the daily care of those who, in the words of one man I worked with for a considerable time, wore "angel suits" and yet were capable of the most perverse and sadistic cruelties.

Various churches have offered some therapeutic services to these child survivors, along with apologies and secret payments of cash, but these are not nearly enough recompense. If those religious bodies so clearly responsible for the abuse and humiliation of children cannot now devote significant parts of their activities and finances to the ongoing provision of medical, psychological and housing services for those they betrayed, then what is the point of them?

The unasked but always present question, hidden within the conversations I have had with people abused in institutions, and conveyed via an astounding variety of metaphors, in many disguises, was, "What lives inside an angel suit?"

In her 1940 essay "The Iliad, or the Poem of Force," Simone Weil wrote:

> The man who is the possessor of force seems to walk through a non-resistant element; in the human substance that surrounds him nothing has the power to interpose, between the impulse and the act, the tiny interval that is reflection.

What happens inside an angel suit is at first an unimaginable state of being – the production of the ways in which a human

being can become a thing. And the traumatised person – the person who has been used as a thing – generates through their grief and rage the wish to make the unimaginable imaginable: a state that others can tolerate thinking about. But this can only happen when those the traumatised are speaking to can themselves see the use of violence, not as a unique and occasional event, but as a marker of the ways in which power is made manifest in daily life: in the demonising of asylum seekers; in the continual imposition of "austerity measures"; in the relentless push to locate all suffering and injustice as personal moral failure.

But the thing about evil is that once it becomes tolerable as a subject for thought, one reaches an understanding that is at first something of an anticlimax, and then gradually becomes more and more chilling: the evil are boring, and boring in the same way, time after time.

Within the inventive aetiologies of evil is a tedious repeating signature. There is no moment of illumination in recognising this. At the heart of evil there is no ultimate insight into human nature. Neither is there lightning, incense, magic sigils or occult meaning. But to find almost nothing at the heart of a human being can be a profoundly disorienting experience.

But in violating the child, the thing inhabiting the angel suit creates a frightening split within the child. Children in this situation come to believe that they contain within themselves an overwhelming badness, and that if they speak of their subjective experience, the badness might rush out and destroy those they love.

It is a terrible mistake to pity the survivors of sexual abuse. They may be terribly vulnerable, but they are nobody's fool.

Children are still aware of how they inhabit their own skin, and how fragile that skin can be, as though a cut in its surface could cause everything inside the child to spill out. A baby's skin is a porous mediating surface that governs and creates a kind of symbolic register. If the baby feels that its skin is not enough

a barrier or enough a container, it will very often create a new skin, a second skin, some way of enabling it to inhabit both the phenomenal and symbolic worlds. Perhaps we should speak of a poetics of skin or skin of poetics.

•

In the hour or so following the end of my work day, I am sometimes in a slow-dreaming, mildly dissociated state, as though, having fallen asleep by a busy highway, I have woken up to find myself on a deserted beach under a red sunset. And as I slowly return to the phenomenal world, the slow-dreaming state gradually dissolves as though the beach were about to reveal objects that might have been sea wrack but are in reality bones or the parts of bodies.

One thing that is so noticeable about violence is how it destroys the capacity to dream. The dream is displaced by the nightmare, a phenomenon that is not merely a dream gone bad but something else entirely. The dream is extinguished in an instant just as those who are subject to aerial bombing by napalm or Hellfire missile ignite like stars and disappear to be replaced by an inconceivable absence.

And in the absence of the thinking person, or the thinking within someone, there arises a sucking void. And all thought is then dragged, distorted beyond recognition, into this unimaginable vortex.

Violence is the conviction that the world is an empty space in which the only quotidian reality is unrelenting terror. It is the conviction that reciprocity and curiosity and understanding must be immediately annihilated. Everybody will be napalmed because the napalm will reveal his or her true nature. Children will be locked up and violated because that is what they are for.

And yet these horrifying realities are not enacted by scheming geniuses but by empty incompetents who have nevertheless become connected to sovereign power. They will forever consider themselves victims, continually threatened, wholly innocent,

possessed of a magical belief in their panoramic intelligence, and always a hair's-breadth from utter panic.

This is the mind, or at least the simulacrum of a mind, that wants to rule the world, that would burn not only the surface of the planet but also its atmosphere and all of space. Still, these minds, as unthinking as the blade of an axe, neither fell from the sky nor came into the world fully formed. We are all made by each other but seem to have no idea how that came about, as though having assiduously collected the materials to incinerate a house we are genuinely puzzled to find that fire reduces it to ashes. We blame the house itself, or those who lived in it, or someone else who was not present, or the materials the house is built of, the timber and the brick.

It is an intolerable circuit, a continual practice of doublethink; armies can free us, poverty is opportunity, weapons bring peace, violence is justice. And this strange displacement, a displacement only possible where an endemic anxiety has replaced all interior capacity for reflection, is what enables the continued production of the cruelties that we will visit upon others.

Author

Stephen Wright writes for *Overland* literary journal, and won the 2009 *Eureka Street* Prize and the 2013 Nature Conservancy Australia Nature Writing Prize. He works as a manager for a non-government organisation intervening with men who use violence and abuse, and as a counsellor engaging in long-term psychotherapy with survivors of childhood abuse.