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Death - the ultimate outcome. Why not measure it in mental health?

(Presentation by Dr Jean Lennane at Health Outcomes conference, Canberra, July 2003

We are not accustomed to monitoring deaths in mental health. Treatment deaths are rare, and deaths from the illness itself, being self-inflicted, or inflicted on others, have so far managed to escape medical and public scrutiny. But should they? Death is after all the ultimate marker of success or failure of medical treatment, and policy changes. Since the late 1980s, 'deinstitutionalisation' in NSW has seen psychiatric hospital beds cut by more than half; and community services - in theory replacing them - cut even more.

With 'deinstitutionalisation' and 'mainstreaming' nationally Australia's beds have been reduced to second lowest in the OECD - beaten only by Turkey. Deaths have risen as bed numbers declined.

Since 1992, NSW Health has collected figures on suicides by clients of the mental health system. However apart from one paper on pooled data from a 39-month period between 1992 and 1995, it refuses to release them. Leaked recent figures confirm such suicides have more than doubled since 1995; and suggest an increase of 5-600% since 1989, to the current rate of 3-4 per week.

No figures have been kept on homicides by people with mental illness, which over the same period have increased from extremely rare to at least one a month, often with multiple victims.

Other medical specialties - e.g. obstetrics, anaesthetics - watch carefully, and learn from their relatively tiny number of deaths. Even a small increase is taken very seriously indeed. It's surely time to 'mainstream' mental health in this vitally important respect.

Mental health mortality figures, 1989 - 2003

1. Homicide: Total figures not available. (NSW Health says it has never collected them.) However the Sentinel Events Review Committee is examining 12 cases that occurred over a 2-year period. These would involve offenders who were hospital inpatients at the time, or had been very recently discharged. If mentally ill offenders who had been denied care, received very inadequate care, or hadn't yet managed to access the system were included, the figure would be at least double, i.e. the NSW rate would be at least one per month. (Often with multiple victims; often children.)

2. Suicide: Figures are very incomplete, as NSW Health has refused to release them even under FOI. Some are definite*; others extrapolated from years where figures were available [ ].

Figures for a 39-month period from 1992-5 were pooled in the only published study. It is wildly unlikely that they were in fact the same each year; far more likely that 1992/3 was lower, and 1995 higher, than the mean recorded of 6.35 total per month.

Year	in-patient suicides	community suicides	total under care	hospital beds
1989	10*	[18]	[28]	>4,000
1990	13*	[23]	[36]	
1991	20*	[36]	[56]	

1992	[23]	[42]	[66]	
1993	27*	49*	76*	
1994	27*	49*	76*	
1995	27*	49*	76*	
1996	[44]	[79]	[123]	
1997	[62]	[110]	171*	
1998	[63]	[111]	[173]	
1999	[64]	[113]	177*	
2000	[60]	[106]	166*	
2001	**?**	**?**	**?**	2,000
2002	**Figures from 2000 onwards are unknown. Anecdotally however it is**			
2003	**clear the death toll has continued to rise. Why the secrecy if it hasn't?**			

Total deaths, mostly preventable, 1989-2000 (12 years) = 1,224
It is likely deaths for the three years 2001-2003 will total 500+.

Note 1: most of the dead were young people with treatable mental illness. (Ages are collected by NSW Health, but do not appear in their 1995 paper. Because they were so young?)
Note 2: deaths caused by deep sleep treatment at Chelmsford were only 1.5 per year, total 40. This was eventually thought worthy of a Royal Commission, albeit also after many years of inaction and cover-up.

The cover-up

How can the preventable deaths of nearly 2,000 people in fifteen years be covered up? Quite easily, it seems. All you need are:

- **a powerless group of victims**, prevented by their illness from forming the effective pressure/lobby groups necessary these days to get even minimum health funding.

- **family and friends effectively silenced** by grief, guilt, and reluctance to identify victims of a stigmatised condition; carers so exhausted by the stress and demands of trying to provide the care the system no longer delivers, they have no time or energy to make a fuss.

-**silent consumer and lobby groups,** set up originally to represent the above, but which have been expertly 'captured' by health departments giving token but vital amounts of funding which then become conditional on the groups not engaging in acvocacy, or otherwise criticising the hand that feeds them.

- **politicians who would rather spend our taxes in more politically rewarding areas**, and are happy to collude with bureaucrats who tell them only what they want to hear.

- **bureaucrats who are willing to do what they're told**, and as long as each does only their own little bit, can avoid facing what they are helping to make possible. (If you want to know more about what bureaucracy is capable of, read Stanley Milgram's

classic, 'Obedience to Authority'.) And have some bureaucrats and politicians decided that death in the early stages of a lifelong and potentially expensive illness is the ideal economic outcome?

- **clinicians who have been cowed into silence**, and hardened their hearts so they can no longer feel the suffering around them.

- **a few who have something to gain** - for their career, or perhaps for their own family member, even if that means hundreds of others will be put at risk

1984, 20 years on. NSW Health discovers Newspeak.

'Don't you see that the whole aim of Newspeak is to narrow the range of thought? In the end we shall make thoughtcrime impossible, because there will be no words in which to express it.' - George Orwell, '1984'

Glossary of Newspeak terms:
'client incident' - suicide while theoretically under care
'critical incident' - homicide by someone theoretically under care
'sentinel events' - potentially embarassing client and critical incidents
'deinstitutionalisation' - closing psychiatric hospitals and replacing them with prisons (aka ***'the least restrictive alternative'***). NSW jails currently house some 900 people with active psychosis. Another 2000 or more have less obvious illness - depression, severe substance dependence, PTSD, severe personality disorders.
'mainstreaming' - an excuse to cut (***'rationalise', 'reform'***) mental health services, 'getting 21st century care in general hospitals', on the grounds that people with mental illness need to be within reach of a CT scanner at all times. Principles and standards of mainstream medicine are however very selectively applied. It has the great advantage that funds can be diverted from mental health to more exciting areas without being noticed.
'lebensunwertes Leben' - 'life unworthy of life'. Nazi term for those whose death doesn't matter, and can be legitimately - and legally - hastened. Not officially adopted here - yet.

How PR and Spin have helped to kill nearly two thousand people in NSW alone

Leaked documents from PR firms involved in 'selling' the closure of Gladesville Hospital in Sydney are instructive. The same techniques and spin have been used in 'selling' other stand-alone psychiatric hospital closures - a process still continuing today. (There is no need for spin when beds in general hospital units are closed, or staff cut in community services. All such measures are 'temporary', 'due to staff shortages', and would never normally be noticed by their communities unless staff tell them - and risk losing their jobs if they do.)
"For residents the issues will be the future of the land - open space, the spectre of medium density residential development etc. When these concerns are addressed, there will be the basis for a strong campaign....We must set the scene where a caring government is taking action in the best interests of patients and the community.....

Terms like 'closing the door on the Dickensian era' and 'fresh start' should be used to stress that this is not just a superficial operation to save money or simply a cover up of an underlying problem....Buildings are Dickensian - totally unsuited to modern and humane treatment. Site is isolated, reinforcing negative attributes.....there is only one solution - physical relocation.....Any savings from the closure will be retained in the psychiatric/mental health budget..... " (PR firm's tender document.)
Of course those same buildings, the same isolated sites, once free of patients instantly become highly desirable to bureaucrats and developers, Dickensian no more.

Stigma

For the last ten years, well-meaning bodies like SANE have pushed the issue of stigma, unfortunately falling into the trap of underplaying the seriousness of mental illness. In guidelines to media that ask them for example to *'avoid language that implies a mental illness is a life sentence'*, they are (a) inaccurate, and (b) depriving the great majority for whom schizophrenia, for example, *is* a life sentence, of the sympathy that would otherwise warrant. Would we give the same message about, say, diabetes?
Or, *'avoid reinforcing myths that people with a mental illness are inherently violent'* - backed up by bureaucratic statements like: "There was no evidence to suggest that people with mental illnesses were innately violent or dangerous towards the public, Queensland Health said yesterday".
This one is literally a killer. Vital words are missing from this mantra -quantifiers like 'some', or 'not all', and the qualifier "if adequately and appropriately treated". The latter omission actually leaves it open to governments not to provide any treatment at all - why bother, if there's no danger in failling to treat?
Trying to remove the 'stigma' of violence by denying it, rather than facing the fact that it is an integral and very serious feature of mental illness for some people, not only contributes significantly to the death toll, but also deprives mental health services of the boost they could get from a link to the 'Laura Norder' auction that happens every election.

Voluntary restrictions on reporting suicide.

Most of the media has taken on board the evidence that reporting of sensational suicides (by popstars and others likely to influence young people; or unusual methods employed by less influential types) can lead to copycat suicides. Here too, however, the baby has been thrown out with the bathwater, and it is now very difficult to get mainstream media to cover suicide at all. SANE has again been influential, no doubt from the best of motives, but the 'voluntary restrictions' on reporting suicide at all have undoubtedly contributed significantly to the tragedy outlined here, and its successful cover-up.

Keeping the lid on:

Silencing staff:
It is now a condition of employment that staff are not to make public statements critical of the system or its policy. In practice, that seems to extend to staff making statements on behalf of a professional body or union, and most are now afraid to disagree openly with Department policy, even in formal or informal meetings at work.

Staff who could and should have given evidence to the recent NSW Parliamentary Inquiry into mental health services were informed of its existence in a memo to Area CEOs dated 9th January, 2002, from the then Acting Director-General. The memo stated:

"If officers from your Health Service intend making separate submissions to the inquiry, they are to be reminded that ***these must be forwarded through the Department so the Minister can be informed,*** *and in accordance with Premier's Memorandum No 98-33 Agency Input to Statutory and Parliamentary committees,* ***'approve of the position being put'."***

The memo appeared to be a response of sorts to a letter from Whistleblowers Australia (WBA) to the Director-General suggesting that he should encourage staff to make submissions to the Inquiry, and guarantee his support and protection for those that did so. Whether or not the memo was intended as a response, it was the only response ever received; and was of course leaked to WBA by concerned staff rather than sent by the Director-General.
A pathologist from the Glebe morgue put in a submission directly, because he was so concerned at the number of cases (suicides and homicides) coming up for autopsy when the system had failed to provide even minimal help. He received a 'please explain' letter within days, and has since left the service.

Denial of access to the figures, even under FOI.

Attempts to get the figures have been consistently frustrated, regardless of who's looking for them. The Institute of Australasian Psychiatrists was denied access in 1993. Figures were later given in the paper published (discreetly, in an in-house journal) in 1995, but pooled so the trend could not be identified. (Obviously in retrospect, the trend was steeply upwards.) Another interesting omission from the paper was the victims' ages, although that was part of the data collected.
In 2001, the National Association of Practising Psychiatrists tried to access the figures under FOI. This was refused. What NAPP understood to be a verbal agreement at a meeting with the Mental Health Unit in 2002 to supply the latest figures turned into a two-year-old copy of a publication on suicide in general in NSW, rather than suicides specifically by clients of the mental health system.
Also in 2001, a journalist from the Sydney Morning Herald tried to access the figures under FOI. This too was refused, though with the generous gesture: "Your application has taken 5 hours and 30 minutes to process so far. As your application is non-personal, a processing charge of $30 per hour is generated. In view of the fact that the Department is refusing to process your application and no documents are to be released, I have decided not to raise a processing charge in this case."
The Parliamentary Inquiry in 2002 also failed to get the figures. It seems that by then the definition had been changed from that under which data had been collected from 1992, to include only deaths found to be suicide by the coroner - a much more restrictive definition. (Coroners in NSW can make a finding of suicide only if proved beyond reasonable doubt. Falling under a train, or from a height, for example, even if known to be depressed, would not normally qualify unless the person left a note stating their intent.)

The SEcRet Committee: NSW Health's latest ploy

The Sentinel Events Review Committee (SERC) was set up by NSW Health in May 2002, apparently in response to pressure to set up a psychiatric deaths committee analagous to e.g. the anaesthetic deaths and maternal deaths committees. NAPP and others pressing for the deaths committee specified that it must be independent of NSW Health, and report directly to Parliament rather than the Department or Minister.

SERC however meets in the Mental Health Unit of the Department; is run by their staff; and *to date its members have not been given the suicide figures either.* Members are sworn to secrecy regarding its proceedings, on pain of $40,000 fine or 6 months' jail; and the Committee will report only to the Health Minister, who is under no obligation to make its findings public. It will not report until 'early next year'. (Remember that every week there are another 3-4 preventable suicides; and every month a preventable homicide, often with multiple victims. A 6-month delay in reporting will see another hundred or so deaths.)

It seems clear from what little has so far emerged from this top-secret committee, that because they too have been denied access to the overall figures, they will be making specific recommendations on the small selection of cases they've been given, e.g. to remove hanging points from units, rather than addressing the real issue, the catastrophic lack of acute, secure, intensive-care, forensic and long-stay hospital beds. But it seems likely its report, if we ever get to hear about it, will be used to claim the problems are being fixed.

Jean Lennane, August 2003

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Update July 2004-

The SERC report **was** released by NSW Health Minister Morris Iemma - two days before Christmas (23.12.03) when no-one was around to notice. You can read it on their website - http://www.chs.health.nsw.gov.au/pubs/n/serc_contents.html
It has received very little attention because it was released so quietly. Also it is - as usual these days- very long, though saying relatively little; and no hard copies were printed for the general public. (You can however get one if you ring NSW Health, ask for the Centre for Mental Health, and nag them.)
Although titled "**Tracking tragedy: a systemic look at suicides and homicides amongst mental health inpatients**", it is by no means comprehensive, which is not surprising given the restricted information available to the Committee. It contains some very strange figures which despite many requests I have not yet been able to have explained. Some time periods are given as e.g. '2001-2002', without saying what period that means; and the truly remarkable figure of '8 possible suicide deaths of patients who were in care as inpatients at the time of their death' is claimed for the period '2002-2003'. On figures already available to me, even if that period was only 12 months (a financial year?) that figure is wildly inaccurate. Possibly someone omitted a zero?
There is however one piece of crucial information - the table of **'reported suicide deaths of patients in contact with mental health services, and all suicide deaths in NSW 1993 - 2001'** on page 13.
This has the numbers of 'reported suicide deaths of patients in care' that I and others had for years been trying in vain to get, even under FOI. They are a little lower than ones I had leaked to me, but not much. (1999 given as 173 rather than 177; and 2000 as 156 rather than 166.) The rise however remains very clear: from 68 in 1993 to their reported maximum of 173 in 1999; allegedly (but very doubtfully) falling to 159 in 2001. The figure for 2002 wasn't given, although since it's collected by NSW Health it must have been available for a report written in late 2003. No prizes for guessing why it was left out.*
Figures for all suicide deaths in NSW were 676 in 1993, and 775 in 2001, an increase of 15%. The increase in suicides in people under care, from 68 to 173 in contrast is of 250%, and has almost certainly been understated. [If figures back as far as 1989 are examined, the rise is more like 500%.] The figures given for 'patients in care as a % of all suicide deaths' in NSW show from 1993 to 2001 that percentage more than doubled, from 10 to 21.

* Figure is given in "Tracking Tragedy 2004" — 179.

So here we are, with official figures confirming what some of us already strongly suspected, that we have a major public health issue killing hundreds of people, mostly young, with treatable illness. Unfortunately it appears that official bodies such as NSW Health are more interested in covering it up rather than addressing the problem. To me, one of the most disturbing things in the SERC table is the increase in patient deaths from 68 in 1993, to 72 in 1994, which then jumped to 100 in 1995, from where it has continued to rise. The only published paper on suicide figures, in 1995, in an in-house NSW Health journal, **pooled those figures.** What serious clinician or scientist, faced with such a drastic increase, would pool the figures so the trend could not be seen, rather than sounding the alarm? How many lives would have been saved if they had taken the sort of action one would expect if such figures started to appear for a physical condition?

The medical profession in pre-war Germany played a significant role in legitimising the extermination of the unfit, which laid the foundations for the Holocaust. Is this another such beginning? And are we as a profession going to continue to stand by and do nothing?

Jean Lennane

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