

## **ELECTION PLATFORM**

By and for consumers and survivors of mental health services



# Victoria's election is coming: 24 Nov 2018 LET'S MAKE IT MATTER

- We call on all political candidates and parties to commit to real change that stops us being hurt.
- We call on consumers and our supporters across Victoria to raise your voices with us. Our issues are serious. Our rights matter. We all vote.



## **About VMIAC**

VMIAC (Victorian Mental Illness Awareness Council) is the peak Victorian non-government organisation for people with lived experience of mental health or emotional issues. Everyone who works here has a lived experience as a mental health consumer.

We provide advocacy, education, consultation and information to promote the rights of people using, or wanting to use, mental health services.

VMIACS's work is premised on the following beliefs:

- People's experiences are respected and valued
- People are experts in their own lives
- People have a right to self determination
- People have capacity to make genuine choices, free from coercion
- People should be safe, respected, valued and informed
- People's diversity is embraced





VMIAC is located on the lands of the Wurundjeri people of the Kulin Nation. We acknowledge the traditional custodians of the land on which we work, and pay our respects to elders past, present and emerging.



# HURT IN HOSPITAL, CASUALTIES IN THE COMMUNITY

Election issues by and for consumers and survivors of mental health services

This document, and a summary version, is available on our website:

https://www.vmiac.org.au/election-18/

Written by VMIAC, August 2018



## Please note

#### **Trigger alert**

This document may contain text or images which are distressing for some people. This is because the content aims to raise awareness of issues related to highly distressing topics within mental health settings. Potentially triggering content includes mention of: sexual violence, child abuse, seclusion, restraint, family violence.

## Acknowledgement of person-preferred language

We acknowledge that some of the language used in this document may be offensive to some people within our lived experience community. As yet, there is no consensus on a preferred term to describe us collectively. Some of the more common preferences include: consumer, survivor, psychiatric survivor, voice hearer, client, person with lived experience, person with mental illness, person diagnosed with mental illness, patient, ex-patient, service user and more. We know that most of us just prefer to be called 'people' whenever possible.

For the sake of brevity and clarity, we have chosen to use:

- 'People': Whenever it has a clear meaning within the context
- 'Consumer/survivor': In major headings, primarily to indicate that preferred language about us varies
- 'Consumer': When we need to differentiates us as a group, throughout text

#### **Acknowledgement of different experiences**

We acknowledge that people have widely varying experiences within mental health services, whether they are clinical, community or disability services. Some people find treatments really helpful, others find them ineffective, others find them really harmful. Some people find staff really respectful, others find them indifferent, others find them really hurtful or even abusive.

This election platform does not aim to provide a balanced overview of the entire mental health sector and of everyone's experience—instead it aims to call out the most serious and harmful issues within mental health services. This means we have naturally focused on people who experience treatments, services and staff as harmful. We recognise that this may feel invalidating for some people who have had positive experiences of services, or staff who provide positive, respectful and supportive care. We want to say that we know there are also positive experiences, and we certainly do not wish to diminish these. We have been mindful of ensuring that the changes we ask for would improve the lives of people being hurt, without taking away from the experience of those who already feel helped.



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## **OVERVIEW**



We represent the **people** that this massive system is supposed to servenot the **sector** 



## > WHO WE ARE

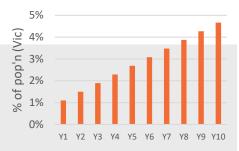
VMIAC is the peak body in Victoria for people who use public mental health services, including public mental health hospitals, community mental health services and the NDIS. All our staff have a lived experience of using mental health services, and every day we listen to people who are hurt, frustrated and losing hope.

We don't represent the sector, or any mental health profession, or industrial body, or families. We are the actual people that this massive system is supposed to serve. Our only interest is that we are safe, treated with dignity, provided quality services, and have our human rights respected and upheld.

## >

## **EVERY YEAR, THERE ARE MORE OF US**

Mental health consumers are often dismissed as inconsequential in the political landscape. Each year, people using public mental health services only make up about 1.1% of the population.



But every year, around 36%¹ of these people are new consumers. This means up to 5% of the population may have been a consumer in the past 10 years. We are growing, we all vote, and we're not happy.



## WHY WE'RE SPEAKING UP

#### Things are getting worse, not better.

Mental health is always in the media. Governments talking about what a great job they're doing. Health services and psychiatrists talking about their innovative research and programs.

We can speak for ourselves, and we have something different to say than the sector

But we're the peak body that represents the most silenced, distressed and marginalised people affected by mental health problems. And our community is saying loud and clear that governments are not listening, services are not helping, and things are getting worse, not better.

## People in power are not listening.

Governments and the mental health sector consult with us a lot. But they're not responding to what we say. It's not good enough to invite us onto a committee if our suggestions and issues are ignored. None of the issues we describe in this paper are new. Each of them destroys lives. We've launched this campaign to bring the focus back to what matters most: people are being hurt and people are not being helped.

<sup>&</sup>lt;sup>1</sup> DHHS. (2017). <u>Victoria's Mental Health Services Annual Report 2016-17</u>, Victorian Govt. Hurt in hospitals, Casualties in the community





## WHY OUR VOICE SHOULD COME FIRST

For too long, governments and the community have listened to the mental health sector, or carers and families, about what we need. Of course, they have a right to speak up.

But we can speak for ourselves—we don't want, or need, others to speak on our behalf. And we have something different to say.

Our basic needs are not being met. Thousands of us are harmed in devastating ways every year—and it's not getting better.



## **OUR ISSUES ARE SERIOUS**

We're not asking for things that are 'nice to have'.

We're asking to be safe, treated with dignity, to be free from violence and abuse, to have our fundamental rights respected, and access to reasonable services that we have a right to.

## >

## OTHER MENTAL HEALTH CAMPAIGNS

We've noticed other campaigns for mental health. We agree with some elements of some campaigns, but we disagree with many.

We remind policy makers that, compared to most other interest groups, we are the only group not looking for more jobs, or a pay rise, or a surplus on a balance sheet.

We just want to be safe, get support to heal, and to have our fundamental human rights respected. We shouldn't have to campaign for this.



## > RECENT FUNDING ANNOUNCEMENTS WON'T HELP

The Victorian state budget gave lots more money to mental health ... to all the wrong places.

The state budget ploughed more money into the very places that hurt us most.

The budget is funding more beds in hospital services, new emergency hubs and a widening of compulsory treatment—all of which signal a shift towards more restrictive, discriminatory and harmful practice.

More spending is only a good idea if you buy the right things. Services in the non-clinical sector are safer, have better evidence, they're cost effective—and we know they're what we actually need. But the budget didn't put any money into this.

Didn't the Commonwealth and state governments just put \$160 million into community mental health?

Yes, they did. But while we welcome this new bilateral funding, it's nowhere near enough. Victoria alone used to fund its community mental health sector about \$110m per year.

This new \$160m is:

- For all of Australia
- Spread over four years

By our calculations, at the *very* best, this extra money will only address 16% of what people need—and possibly a lot less. We have to do better.

People living with extreme mental and emotional distress have a right to habilitation and rehabilitation services—but somehow, it's all just disappeared in Victoria.





- Affordable
- Easy access
- Rights-based
- Preventative, healing, recovery
- More of these reduces demand for crisis & disability services
- What consumers want and need

- Expensive
- Hard to access
- Rights breaches
- Crisis focused
- Giving up on recovery
- What consumers don't want

Without adequate support, habilitation and rehabilitation services, we won't just go quietly away.

We'll turn up to emergency departments in crisis, or develop substance use problems, or become or stay homeless, or die from suicide.

These consequences are devastating for us—and they will cost the government, community and our loved ones far more than just doing the right thing in the first place.



## **THREE SERIOUS ISSUES**

VMIAC is campaigning about three issues this election. These include:



## Hurt in hospital

Consumers continue to experience serious physical and psychological harms in Victorian mental health hospital units.

The sector is not accountable enough, and government provides little transparency.



## Sexual violence in hospital

Despite more than 25 years of reports on this issue, Victorian hospitals & governments have failed to protect consumers from sexual violence while in hospital.

The recent report by the Mental Health Complaints Commissioner is damning.



## Casualties in communities

Thousands of distressed Victorians can no longer access any non-clinical community support or rehabilitation services. People with psychosocial disability are being locked out of the NDIS, and the community support sector has been decimated.



## WHAT WE WANT

We call on political candidates and parties to commit to:

## Hurt in hospital

- 1. Fund a new initiative to limit predictable harms from compulsory treatment and restrictive practices
  - Implement our recommendations to reduce predictable harms from compulsory medication
  - Improve understanding and responses to emotional injury from current harmful practices
  - Improve human rights protections, sector accountability and safeguards, including access to legal representation
- 2. Fund a pilot for a new, improved kind of crisis service
  - Other countries have successfully established contemporary, safer, more effective, consumer-led
    crisis services. It's time for Victoria to get with the program. We call for a pilot in one catchment
    area of Melbourne.

## Sexual violence in hospital

PART A: In response to 'The Right to be Safe' report

- 1. Act now and implement urgent actions that rapidly improve safety
- 2. Commit to addressing implementation risks and fund at least \$40m to begin implementation

PART B: Recommendations beyond 'The Right to be Safe' report

- 3. An acknowledgement and apology
- 4. Response for historical survivors
- 5. Address risks from staff

## Casualties in the community

- 1. Hold the Commonwealth government accountable for serious NDIS failings
- 2. Fund a new kind of service: 'Walk-in community support', in every catchment area of Victoria
- 3. Fund VMIAC to provide an independent advocacy and peer support to people struggling to access the NDIS
- Fund a coproduced project to understand and address widespread support, habilitation and rehabilitation gaps for consumers following five years of disruptive sector change



THE DETAILS

**POSITION** 

1



## **HURT IN HOSPITAL**

Physical and psychological harms in Victorian mental health hospital units



## 1 Hurt in hospital

The type of abuse shown in movies like 'One Flew Over the Cuckoo's Nest' is long gone. But abuse still happens. Contemporary psychiatric services are not safe or effective for many people.

## THE ISSUE

Many people are harmed by hospitals as a consequence of mental health unit admissions. Common causes of harm include:

- Long-term psychological harm caused by unsafe psychiatric practices. Many people experience emotional damage from compulsory detention, compulsory treatment, restraint and high rates of seclusion. Outrageously, Victorian hospitals do not even measure or monitor the use of chemical restraint.
- Average time people are locked in seclusion rooms (worst in Aust)
- Early death and disability can be a consequence of treatment with some psychiatric medications. Most people are treated by force with these medications, and many people are not even told about the risks, or provided with simple preventative treatments or services.



We die about two decades before other Victorians. In part due to side effects from medications most of us are forced to take.

- 3. Little accountability in the public psychiatric system
  - means that many harms are kept secret, and there is little pressure to change. There are lots of reports about mental health, but much important data is missing, and what data we have is fragmented. Very little information is reported on a service level, as we have come to expect for other public services like schools. This allows poorly performing hospital mental health services to remain hidden and unmotivated to change.
- 4. Many people do not receive appropriate or helpful treatment. Public psychiatric services are increasingly unfit for purpose, with an unbalanced workforce and an increasing lack of skills. Almost noone receives psychological therapy or counselling as treatment—it's all about pills and electro-convulsive therapy.





57% of adults are forcibly detained, treated & traumatised





## **VMIAC'S POSITION**

It is unacceptable that people in extreme emotional distress can leave a public hospital feeling more traumatised than when they arrived.

- Victoria's public clinical mental health services should be safe for consumers. This includes mental and emotional safety, not just physical safety
- People should leave a mental health service feeling emotionally, mentally and physically understood and supported
- Forced treatment should never be used, but while it is still common, forced treatment should never be used if side effects cause significant illness, disability or reduced life expectancy
- Every person using mental health services should be fully informed about the risks of psychiatric medication and electro-convulsive therapy, regardless of whether they are voluntary or compulsory
- Every person facing compulsory treatment should have access to complete procedural fairness, including access to legal representation

## It is unacceptable that Victorian public mental health services have failed to respond to the fundamental needs of people using their services.

- Victoria's public clinical mental health services should be fit for purpose. The clinical mental health
  workforce make-up should include a high proportion of counselling and therapy experts, rather than
  primarily nurses and psychiatrists
- The use of compulsion and control, and overly medicalised approaches to human distress, have become institutionalised. There are much better models of care available to our citizens, and it is time to pilot them
- A safe, high quality, rights-based mental health system must include substantially improved comprehensive, transparent data, including by local service-level

# We cannot support increased beds in clinical services given the levels of harm

- We acknowledge that some people find mental health hospital admissions helpful, however this is not good enough while the majority of people are treated by force and so many are left with life-long trauma.
- We acknowledge that many people desperately seek hospital services and can't get in—but we



believe there are less harmful, more helpful services which could be provided in the community.



## **OUR CALL TO ACTION**

We call on political candidates and parties to commit to:

## Fund a new initiative to limit predictable harms from compulsory and restrictive treatment

#### a) Reduce predictable harms from compulsory medication

- Set maximum limits on doses of compulsory medication, and disallow polypharmacy in compulsory treatment. Many of these medications are dangerous. Forced treatment is bad enough, but forced treatment without limit is unacceptable.
- Establish protocols to cease compulsory treatment if serious physical health side effects occur, such as movement symptoms, metabolic and cardiovascular conditions, hormonal or sexual changes, cognitive impairment, or other side effects which distress the person.
- Establish protocols to ensure all consumers are informed of mortality and physical health risks from medication, advised of strategies to reduce risks, and supported to access relevant health services (eg, physiotherapy, dieticians, health psychology—with mental health expertise) as required.

#### b) Improve understanding and responses to emotional injury from current harmful practices

- Research and address the traumatic emotional impacts of compulsion
- Co-produce comprehensive education for the clinical workforce on strategies to reduce harm and provide improved emotional support to consumers

### c) Improve human rights protections, sector accountability and safeguards

- Increase funding so all consumers can access a lawyer for Mental Health Tribunal hearings.
- Dramatically improve public reporting of major harms, including a pilot program to report on chemical restraint.
- In the 2019 review of the Mental Health Act, upgrade Advance Statements to Advance Directives, and include 'blocked' persons as well as nominated persons.

## 2. Fund a pilot for a new, improved kind of crisis service

There are much more helpful, contemporary, less dangerous, more affordable alternatives to the current hospital-based system of acute mental health care.

Other countries have excellent models for Victoria to emulate, such as <u>Piri Pono</u> in New Zealand, <u>Afiya</u> in the USA, and the <u>Leeds Survivor-Led Crisis Centre</u> in the UK.

## Fund a pilot of a new consumer-led, peer crisis service

• Establish the pilot in one catchment area of Victoria, and compare to a similar catchment for outcomes. The pilot can demonstrate contemporary, safe and effective mental healthcare models for the future.



## **BACKGROUND**

## Behind closed doors...

Unsafe practices in mental health hospital units have a long history—but they're often hidden from public view, literally behind closed doors.

What happens in these services is helped to remain hidden because of:

- A lack of transparent public reporting about many troubling issues
- Commonly held discrimination and myths, meaning that the media and public may not even care to ask a lot of questions.



## Common myths

These myths may contribute to people thinking it's OK to treat us so badly:

MYTH	FACT
People diagnosed with mental illness are dangerous	People diagnosed with mental illness are no more dangerous than anyone else—but they <u>are</u> at much greater risk of being a victim of violence. <u>Read more</u> by SANE.
Healthcare workers are at risk of violence by mental health patients—so this justifies restrictive treatment	As consumers we know that restrictive practice is a cause of aggression, not a solution. It's true, sometimes consumers are aggressive towards staff, but often this is self-defence against forced medication or electroconvulsive therapy. It is natural to try and protect yourself from harm. The best way for staff to be safe is to ensure that consumers are safe too. Read more in this DHHS handout.
People just need to take their medication and they'll be OK—so this justifies forced medication	There is no psychiatric medication that is effective for everyone, many people find that no medications are helpful, and many even find them harmful. Psychiatric medications can cause serious side effects that can be life-threatening or cause permanent disability. Read more about the risks of antipsychotic medication.

Sometimes, public campaigns inadvertently contribute to these harmful myths:

Recent WorkSafe campaigns about safety for healthcare workers doesn't target mental health, but they are still painful for many mental health consumers to watch.

Mental health consumers are often the victim of violence by healthcare workers—yet we would never see TV ads about our experience







## Long-term psychological harm from unsafe psychiatric practices

There are too many practices within mental health hospital services that can cause emotional, or psychological harm to people who have to stay there. This section outlines some of the most common issues.

## Compulsory detention and treatment is far too common

Most people in mental health hospital units are treated by force: 56.9% of Victorian adult admissions are compulsory<sup>1</sup>, much higher than the national average of 48.2%<sup>2</sup>, and in defiance of criticism by the United Nations<sup>3</sup>:

Justification for using coercion is generally based on "medical necessity" and "dangerousness". These subjective principles are not supported by research and their application is open to broad interpretation, raising questions of arbitrariness that has come under increasing legal scrutiny. "Dangerousness" is often based on inappropriate prejudice, rather than evidence. There also exist compelling arguments that forced treatment, including with psychotropic medications, is not effective, despite its widespread use.

Compulsory detention and treatment can be psychologically harmful for many people<sup>4</sup>. It breaches multiple human rights, serves no therapeutic purpose, and can be harmful by recreating original experiences of trauma that led to mental health problems in the first place.

It makes no sense that a service treats people with emotional distress by causing even more emotional distress.

## High rates of seclusion

Seclusion can be a terrifying experience, and mental health services use it regularly. It can leave people with lifelong traumatic impacts. Some people describe it as torture.

of your life. You're terrified.

Now imagine being locked into a tiny, bare room, with only a plastic mattress on the floor, and a disposable

Imagine the most distressing moment

cardboard bedpan in the corner. You're left there, alone, for 10 hours. Locked up for

Locked up for

(VIC average seclusion)

Is this acceptable health 'care' for Victorians?

Is it acceptable that the rate of secluding adolescents is growing rapidly?

<sup>&</sup>lt;sup>2</sup> AIHW. (2017). *Mental health services in Australia—Restrictive practices report.* 

<sup>&</sup>lt;sup>3</sup> United Nations Human Rights Council. (2017). Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, s.G.64.

<sup>&</sup>lt;sup>4</sup> National Mental Health Commission. (2015). <u>Position Statement on seclusion and restraint in mental health</u>.



In Victoria seclusion lasts for 10 hours<sup>1</sup>, on average. We're one of the worst performing states in Australia<sup>2</sup>. Seclusion rates have risen by 347% for teenagers<sup>5</sup> in mental health hospital units over the past 15 months.

Even people who are never secluded are traumatised. VMIAC members tell us about watching fellow patients being dragged into seclusion while screaming for help, and are terrified it might happen to them.

New Zealand has <u>committed</u> to ban this barbaric practice by 2020, after condemnation by the United Nations. Last year a <u>NSW woman</u> died after being secluded in appalling conditions. This is not mental health 'care'—it's creating even more mental health problems.



## Chemical restraint is not even measured



Chemical restraint is the practice of intentionally sedating people in order to 'control their behaviour'.

Anecdotally this practice happens often in psychiatric services, but we can't report statistics because we don't even measure chemical restraint let alone report on it. Many consumers experience significant fear at being forcibly sedated, distress during the experience, and trauma afterwards.



## Physical & mechanical restraint

People may be surprised to learn that restraint is still used in psychiatry. In fact, during 2016/7, there were **7,215** episodes of restraint in Victorian public mental health services<sup>6</sup>.

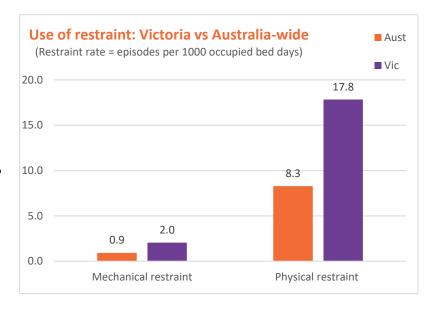
**Mechanical restraint** is the use of straps or belts to tie a person down to prevent movement.

Physical restraint is the use of (usually multiple) staff to hold a person down to immobilise them.

## We can't tell you:

- How many people were restrained?
- How many people were injured during restraint (physically or emotionally)?
- How many people were restrained at each different hospital?

Because this data isn't reported publicly.



<sup>&</sup>lt;sup>5</sup> DHHS. (2018). <u>Child and Adolescent Mental Health (CAMHS) Performance Indicator Reports</u>, Vic Gov.

<sup>&</sup>lt;sup>6</sup> Chief Psychiatrist of Victoria. (2017). <u>Chief Psychiatrist's Annual Report 2016-17</u>, DHHS, Vic Gov.



## Invisible harms from Electro-Convulsive Therapy (ECT)

Electro-Convulsive Therapy (ECT, or 'shock treatment') is still commonly used in mental health services, with a consistent average of 11-12 treatments per person. ECT seems to be given more commonly to older Victorians: people over 65 years of age make up about 10% of all hospitalisations, but account for approximately 36% of ECT treatments.

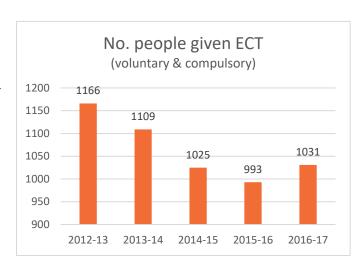
ECT is a controversial subject, with many people saying, 'It saved my life' but many other people saying, 'It ruined my life'.

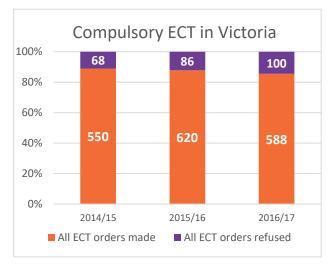
Possible reasons for these divergent views are that:

- ECT can cause severe cognitive impairments, (particularly memory loss) in some people
- Having ECT against your will can influence your views about it
- ECT has much weaker evidence for use with schizophrenia than with depression
- Research suggests any positive effects of ECT are short-term, so it might depend on when you ask

What is clear is that most consumers want:

- Much clearer information about the risks of ECT
- To retain choice about having a procedure like ECT
- To know how many people are experience cognitive impairment from ECT, and what's provided for those people





## Important things that are not reported...

## How many people get ECT against their will?

We know how many compulsory ECT orders are made each year, but *not* how many people are affected (because some people have multiple orders made within a year).

## How many people end up with cognitive impairment from ECT?

We cannot report how many people sustain long-term cognitive impairment from ECT, or the seriousness or permanence of those impairments, because this data is not reported.



## A lack of procedural fairness... and a lack of visible processes

Victoria's Mental Health Act permits a wide range of human rights breaches by mental health services. The Act is also supposed to provide some level of procedural fairness, that is, protections, oversight and safeguards.

We know from many years of advocating with and for our fellow consumers, that these protections do not always work. Particular issues regarding procedural fairness include:

#### **Hearings before the Mental Health Tribunal:**



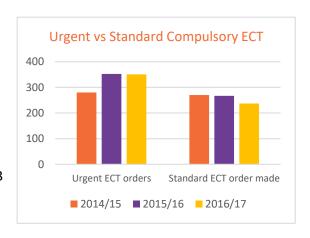
People who receive compulsory treatment have a hearing before the Mental Health Tribunal, with a chance to appeal their detention and treatment, but:

- Only about 10% are able to access a lawyer to represent them
- Anecdotally, we hear occasional, concerning reports from consumers about:
  - Not being given adequate notice of a hearing
  - Being required to take sedating medication before a tribunal hearing

#### 'Urgent ECT'

'Urgent ECT' is a loophole in the Mental Health Act which can remove all the protections for a compulsory ECT hearing (time to prepare, to access an advocate and/or lawyer).

A service just has to say that a person needs 'urgent' ECT and a hearing can be held in as little as a few hours. We know that the rates of urgent ECT vary considerably by service, and that they make up an increasing proportion of compulsory ECT: in the past 3 years, 'urgent ECT' has gone from 50% to almost 60% of all compulsory ECT.



#### **Advance statements**

Advance statements are a way for people to document their treatment will and preferences ahead of time. If hospitalised, an advance statement must be considered by the treating psychiatrist, but it doesn't have to be upheld.

Since being introduced, only about 2% of all inpatients have an advance statement. Our recent survey of consumers suggests this is in part because of poor promotion. However, a more serious concern is that 73% of survey respondents were unconvinced that a public hospital psychiatrist would respect or uphold them. We urge political candidates to change these into advance directives when the Act is reviewed in 2019.

"The doctors and hospitals, they don't care what you want they just do whatever they like."

Consumer respondent, Survey on advance statements & nominated person (2018)



## Early death, disability and new physical health conditions as a consequence of compulsory treatment with some psychiatric medications

Many psychiatric medications, particularly 'antipsychotic' drugs, have serious side effects, and these can cause people to develop new health problems, disability and even contribute to a reduced life expectancy.

## Serious, unchecked risks from 'anti-psychotic' medications

In 2017, the National Mental Health and Consumer Forum commissioned Curtin University to conduct a study, and produce a consumer and family guide<sup>7</sup> about the impacts of 'anti-psychotic' medications commonly used in psychiatry. This is just one group of psychiatric medications, but they are commonly used in our public mental health services, and often against people's will.



Antipsychotic drugs are associated with many direct harmful and unwanted effects. Sometimes these effects can be experienced as worse than the problem they were intended to relieve. Common side effects of antipsychotics include:

Movement symptoms such as trembling, muscle stiffness, slowness of movement, shuffling walk, restlessness in the legs, twisting movements of the body, grimacing, uncontrolled movements of the tongue, lip puckering, and rapid eye blinking.

**Tardive dyskinesia** (TD) is a serious neurological disorder caused by antipsychotic drugs that impacts both muscle control and thinking and cognition. Rates of TD are extremely high and increase with each year of exposure to antipsychotics.

Metabolic and cardiovascular changes such as increased or decreased appetite, weight gain, diabetes, increased blood glucose and cholesterol levels, changes in blood pressure,

and irregular heartbeat.

Hormonal and sexual changes such as excessive growth of hair, acne, painful and swollen breasts, breast enlargement in men, unusual secretion of breast milk, changes in menstrual periods, decreased libido, impaired arousal, and impaired orgasm.

Cognitive changes such as tiredness, drowsiness, feeling sedated, difficulty concentrating, forgetfulness, confusion, dizziness and changes in sleep.

**Emotional changes** such as feeling anxious, nervous, depressed or agitated.

Other side effects include dry mouth or excessive saliva, blurred vision, constipation, diarrhoea, difficulty urinating, headaches and vomiting.

Other types of psychiatric medications also carry risks, including:

- Antidepressants
- Mood stabilisers
- Anti-anxiety medications

## Imagine if cancer patients were...

- Not told the risks of chemotherapy
- Given chemotherapy against their will
- Denied treatment for chemo side effects

Many psychiatric medications are just as risky as chemo, but all these practices are common in mental health units.

<sup>&</sup>lt;sup>7</sup> National Mental Health Consumer and Carer Forum., and Curtin University. (2017). <u>What you may not know about antipsychotics: A quide for people taking antipsychotic drugs and their supporters.</u>



## Little accountability means that many harms are kept secret

The Victorian Government's own website<sup>8</sup> says it aims to: *Build public trust in government by moving beyond compliance, and taking a proactive approach to accountability, transparency and integrity.* Yet government funded public mental health services are a long way from demonstrating even compliance, let alone accountability, transparency and integrity.

The new annual report was a beginning, but it has too much 'PR' and too little hard data on critical areas. We were encouraged that the current Victorian government introduced an annual report to parliament about public hospital mental health services, but disappointed in its execution. Much more data is required in public reports if there is a genuine concern to reduce harms and improve human rights in hospitals.

Listed below are just some of our concerns about the lack of transparency in government reports:

Lack of service-level reporting: Most data is only provided at a state-wide level, and is not reported by service. This is unacceptable for a system which has such extraordinary powers over citizens, and where many harms are known to occur. Individual services must be held to higher levels of public, transparent accountability.

Data sometimes unnecessarily complex:
Some data is reported in complex ways which are difficult to understand. This may be helpful for government statisticians, but not for the community. For example, seclusion is reported as 'number of episodes per 1000 occupied bed days', rather than 'number of people secluded' and 'percentage of all inpatients secluded'.

Basic data not provided: Some very basic data is not reported, such as how many people are inpatients of mental health hospital services, or how many people receive outpatient services. This makes other data less meaningful. For example, reports tell us that 11% of people using community mental health services are on treatment orders, but they don't say how many people use those services. So we are left asking: '11% of what?'

**Sexual violence:** There has been no public reporting on the number of sexual violence incidents, reports to police, referrals for counselling, or the category of perpetrator, and no reports about the use of women-only areas.

Human rights breaches: Human rights breaches are common in these services, yet there is no reporting on the most common breaches, on lawful and unlawful breaches (both of which occur), or access to, and use of, remedies.

Harms from compulsory treatment: There is no reporting on harms such as cognitive impairment caused by ECT. If people are forced to have these treatments, consequences such as these must be made transparent.

Treatment practices: There is no reporting on the treatments actually provided by public mental health services. What proportion of people access different treatments (eg., medication, ECT, different therapy types, referrals)? How do these align with relevant standards (eg., prescribing rates, polypharmacy, etc)?

Restrictive practices: Reporting on seclusion has improved somewhat, but public reporting on restraint is poor, and there are no reports at all on chemical or emotional restraint. There is no reporting on physical or emotional injuries sustained by consumers because of restrictive practices, and no reporting on the standards of seclusion facilities.

Procedural fairness: Consumers tell us about many instances of unfair processes while trying to retain their rights and freedoms. Just some areas that need more transparency include: access to lawyers, service compliance with advance statements, the incidence of undue influence, sedating medication prior to tribunal hearings, misuse of 'urgent ECT' as a way to avoid rights protections.

**Outcomes:** The DHHS annual report uses a poor measure for outcomes (the 'HoNOS scale). It is well understood that HoNOS does not measure recovery, yet it's reported as though it does.

Consumer experiences: A consumer experience survey is conducted each year at each service (the YES survey) but the results are not released. It is difficult to see the point of this survey if the results remain secret.

Physical health: There is no reporting about the number of people who develop serious physical health conditions and disabilities as side effects of forced and voluntary medication—even though it's well accepted that these contribute to our reduced life expectancy. There is no reporting on physical health service provision or availability.

Disrespectful & stigmatising reporting: The DHHS annual report outcome 'Victorians with mental illness live free from abuse or violence and have reduced contact with the criminal justice system' is offensive because these are two very different experiences. Worse, the department only reports on people in prison with a psychiatric rating. This is disrespectful because around 85% of us are survivors of violence and abuse<sup>9</sup>, and offensive because we experience widespread discrimination based on myths that we are violent<sup>10</sup>.

Fragmented reporting: Lots of important data about public mental health services is distributed across many different reports. This makes it extremely difficult to know what is actually occurring in a complex and sometimes harmful system. We expect that the DHHS annual report (a) draws together key information from these other reports, and (b) makes clear reference to all other reports which provide detailed information.

<sup>8</sup> https://www.vic.gov.au/publicsectorreform/accountability.html

<sup>&</sup>lt;sup>9</sup> Goodman, L.A., Salyers, M.P., Mueser, K.T., Rosenberg, S.D., Swartz, M., Essock, S.M., Osher, F.C., Butterfield, M.I., and Swanson, J. (2001). *Recent victimization in women and men with severe mental illness: prevalence and correlates.* Journal of traumatic stress, 14:4, 615:632. AND Read, J., Fink, P.J., Rudegeair, T., Felitti, V., and Whitfield, C.L. (2008). Child Maltreatment and Psychosis: A Return to a Genuinely Integrated Bio-Psycho-Social Model. Clinical Schizophrenia & Related Psychoses

<sup>&</sup>lt;sup>10</sup> SANE Australia. (n.d.). Facts VS Myths: Mental Illness and violence.



## Public mental health services are increasingly unfit for purpose

Failure to provide appropriate treatments and services

Many people in society develop mental health concerns, but only about 1.1% end up admitted to hospital for treatment each year. Of these people, around 85% have a history of profound trauma, with around two-thirds having experienced child abuse. <sup>9,11</sup>

In practice, few public mental health services, particularly inpatient types, offer any kind of psychological therapy, counselling or support groups.

There is a common misconception that psychiatrists in hospital provide psychological therapies. This may happen in private services and private consultations, but it is almost non-existent in public hospital services. Instead, psychiatric treatments in public hospitals are almost exclusively about prescribing medications and/or electroconvulsive therapy. Many people are not even asked about their history of trauma and abuse, let alone provided support for it.

The mental health workforce is out of balance and being increasingly deskilled

- The public mental health workforce is almost entirely comprised of nurses and doctors, with a smaller group of unspecified 'allied health and diagnostic professionals'.
- Mental health nurses only complete one year of post graduate mental health study after a general nursing degree. This is insufficient to provide appropriately skilled practice.
- o Public hospital psychiatrists rarely if ever practice talking therapy
- o Increasingly, both mental health nursing and psychiatric training is taken online, leading to a lack of critical interpersonal and therapeutic skills
- The most skilled clinicians usually work in community clinics and the least skilled and least experienced usually work in inpatient settings. This is both risky and unhelpful.
- o There is minimal access to therapists and counsellors, and often none at all
- Support groups have almost disappeared from hospital units
- Physiotherapists and dieticians are not well provided to support people to understand and adjust to
  the sedating effects and metabolic impacts from psychiatric medication. These kinds of allied health
  supports are much better provided in health areas like oncology, but are almost non-existent in
  psychiatry. This is a serious healthcare inequity.

## Did you know?

Psychiatric medications can contribute to our 20 years reduced life expectancy:

Antipsychotic side effects

Obesity

Diabetes & other disorders

Early death

## How do medications make us obese?

This is thought to be because psychiatric medications can:

- Stimulate appetite (so we eat more)
- Be sedating (so we exercise less)
- Affect our metabolism (making it all harder)

Given these side effects—PLUS the fact so many of us are forced to take these medications against our will—imposes a responsibility on hospitals to provide:

- Mandated information about side effects
- Access to health monitoring and screening
- Access to funded physiotherapy and exercise programs to work out how to stay fit when sedated
- Access to funded dieticians to work out how to live with appetite stimulation

We believe compulsory medication must be ceased if or when side effects start risking our health.

<sup>&</sup>lt;sup>11</sup> Office of the Chief Psychiatrist. (2011). <u>Service Guidelines on Gender Sensitivity & Safety: Promoting a Holistic approach to wellbeing</u>. Mental Health, Drugs and Regions Division, Victorian Government, Department of Health, Melbourne, p.10.



## What do we mean by peer-run services?

Many people experiencing mental or emotional distress go to hospital Emergency Departments (EDs), or get admitted to mental health units, to seek help or safety. Sadly, these are not always a helpful option, and sometimes they are even harmful.

If we keep doing what we've always done, we'll keep getting what we've always gotten.

Peer-run services offer an exciting, contemporary new approach to mental health services:

There is a small but steadily growing number of research studies showing that services controlled and run by people with lived experience of mental illness ("Consumer-operated services") are



effective in supporting recovery. Such services tend to be characterized by consumer control, choice, voluntary participation and opportunities for decision-making by consumers (Holter et al 2004).

Most of the evidence for the effectiveness of consumer-operated services comes from the United States, where three large studies have each published multiple papers on their findings....

They found that people who accessed consumer-operated services experienced improved levels of empowerment, social inclusion, well-being, housing, employment, hope and program satisfaction, than those who accessed only traditional services.<sup>12</sup>

### Peer-run services are different in lots of ways

The most obvious is that that controlled and staffed by people with a lived experience of mental and emotional distress and trained as peer workers. They are voluntary and promote empowerment and choice. They even look different...

These are images from a typical hospital...





Which environment would YOU prefer in the midst of mental and emotional crisis?

And these are some leading crisis alternative services from overseas...









## Let's look to countries who are leading the way in service innovation

Peer-run crisis services operate in the US, UK and New Zealand, and are attracting increasing interest. They are preferred by people who use services, they don't use restriction or compulsion, and they're much more affordable than expensive hospital-based services.

There is good evidence for peer-run services. A leading review into consumer-run services, commissioned by the Mental Health Commission of NSW, 12 recommended 'Greater investment in consumer-operated services be considered, with consumers centrally involved in conceptualising, designing, operationalising and evaluating these services.'



VMIAC recommends two services to use as models for a pilot residential service in Victoria:

- Piri Pono (New Zealand) Read more
- Afiya Peer run respite (USA) Read more

And another service which is a great model for a non-residential service:

• The Leeds Survivor-Led Crisis Service (UK) Read more



Image source: Western Massachusetts Recovery 13

#### Watch this video to learn more about the Afiya program:



<sup>&</sup>lt;sup>12</sup> Grey, F., and O'Hagan, M. (2015). *Evidence Check: The effectiveness of services led or run by consumers in mental health.* Mental Health Commission of New South Wales, Sax Institute.

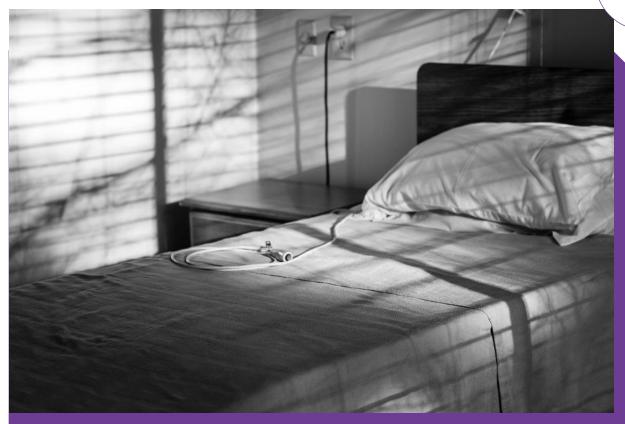
<sup>13</sup> http://www.westernmassrlc.org/afiya

<sup>&</sup>lt;sup>14</sup> https://www.youtube.com/watch?v=9x8h3LvEB04&feature=youtu.be



**POSITION** 

2



# SEXUAL VIOLENCE IN HOSPITALS

The failure of Victorian hospitals & government to protect patients from sexual violence



## Sexual violence in hospitals

## THE ISSUE

## Consumers in mental health hospital wards across Victoria are not safe from sexual violence

Sexual violence in hospitals is almost unimaginable, but it happens in hospital mental health units ... sexual assault, sexual harassment, and not feeling safe from sexual violence.

Men and women are locked in together. Many bedroom doors can't be locked. Survivors are often not believed by staff. Services knowingly force people into dangerous situations with no way to protect themselves.

A damning report on sexual violence in was released by the Mental Health Complaints Commissioner in March

mental health services this year.

## Hospitals are supposed to be places where people feel safe. Except for us.

Sexual violence has been a serious issue in mental health services for many years, with public advocacy campaigns since 2007 by the Victorian Women's Mental Health Network and VMIAC.



25 years on, and we're still writing reports about people being hurt in hospital.

The recent report 'The Right to be Safe'15 by Victoria's Mental Health Complaints Commissioner (MHCC), investigated 90 complaints about the lack of sexual safety in mental health services. Reported issues include sexual assault, sexual harassment, and negligence by staff and services to provide a sexually safe environment, such not allowing people to lock their bedroom doors. Assaults and harassment have been carried out by both copatients and by hospital staff.

This issue has been well-understood for decades—yet neither health services, nor governments, have taken adequate action to ensure that patients are safe.

**VMIAC** acknowledges the countless people, over many years, who have survived

sexual assault, sexual harassment, and not

feeling safe while

services.

using mental health

We acknowledge that

promise to keep us safe

continue to fail in their

duty. We acknowledge

never even believed, or

that many of us were

offered support, or

provided with justice.

We acknowledge the

ongoing trauma of these experiences in many aspects of

people's lives.

the services who

<sup>&</sup>lt;sup>15</sup> Mental Health Complaints Commissioner. (2018). The Right to be safe. Ensuring sexual safety in acute mental health inpatient units: sexual safety project report, Vic Govt.



## **VMIAC'S POSITION**

1. It is unacceptable for any person to experience sexual violence, or not feeling sexually safe, in a public hospital.

It is unimaginable that many people live with a realistic fear of rape if they are readmitted to hospital. Given that the majority of us are forcibly detained makes it even worse.

2. Successive Victorian governments have failed to ensure that health services keep mental health consumers safe from sexual violence.

It is the responsibility of every Victorian Government to ensure:

- Safety: That people are safe while using public services
- Accountability: That the health sector is adequately and transparently held to account
- Resources: Sufficient information, funding and resources are made available to ensure safety
- **Continuous improvement:** As recommended in the Targeting Zero Report (Duckett, 2016), safety improvements must be monitored, evaluated and adapted as needed

In relation to sexual violence in hospital, there has been failure in all areas.

3. We support the 'Right to be Safe' report by Victoria's Mental Health Complaints Commissioner, but we have concerns about the likelihood of the report being successfully implemented by the sector and government.

In particular our concerns include:

- This requires large-scale, complex, expensive and culture-challenging change
- The mental health sector has largely failed in implementing change of a comparable scale, such as recovery-oriented practice
- There is a lack of existing and effective change processes and mechanisms in mental health systems
- The need for significant and sustained government funding and sector effort

## 4. The rights of survivors

People who have been hurt by sexual violence or not feeling safe, while in hospital, deserve an acknowledgement and apology, avenues to be heard and believed, and access to support and justice services. Not just in response to services failing in their duty to provide a safe space, but in failing, over many years, to even believe or acknowledge survivors of sexual violence.

Consumers are required to use their local hospital mental health service, often against their will. At the very least, people deserve to know how dangerous this hospital might be.



## **OUR CALL TO ACTION**

We call on political candidates and parties to commit to:

## PART A: In response to 'The Right to be Safe' report

VMIAC has developed a separate paper on sexual violence in hospitals, which provides a detailed response to the Mental Health Complaints Commissioner's (MHCC) 'The Right to be Safe' report. This election platform highlights our most critical concerns.

## Act now and implement urgent actions that rapidly improve safety

VMIAC has identified a set of recommendations from 'The Right to be Safe' report which require immediate, urgent implementation (see over).

All of these are indisputably necessary, easily achievable, a relatively small cost and will make a quick and real difference in the areas of highest risk.

We remind political candidates that people are scared or actually being hurt right now while you read this paper. Please stand up for us.

## 2. Commit to addressing implementation risks and fund at least \$40m to begin implementation

VMIAC has concerns about the likelihood of 'The Right to be Safe' report being successfully implemented, as outlined in the previous section. We call for the following actions to help ensure successful implementation of the report.

- a) **Significant and ongoing funding commitment:** We call for a significant funding commitment to prevent sexual violence, including up front and into the future. We're not in a position to estimate the full costs of this work, but we know that anything less than \$40m in the first year will be tokenistic, and dedicated funding will be required for at least five years.
- b) Commit to update statements of priorities to ensure serious buy-in at the highest levels: We urge swift action on recommendations for sector governance. Without serious buy-in at the highest levels this will not succeed. We strongly endorse changes to statements of priorities, accessible public reporting at a service level, and other ways to engage and motivate hospital boards.
- c) Commit to review and overhaul government-led change processes in mental health: Change management processes and implementation mechanisms used by the sector and DHHS are too often superficial, short-lived or ineffective. The basics of leading change in this sector needs to be redeveloped to ensure genuine, sustainable, and continuously improving change of a demonstrably high standard. For example, we have particular concerns about the lack of sector compliance with Chief Psychiatrist guidelines, the ineffectiveness of risk assessments,

and an over-reliance on documentation and brief training programs (see the background section for more information).

change anything. We need real action.

d) **Independent oversight:** We know from the child abuse royal commission that it does not work to ask large, powerful institutions to self-manage harms caused to people with little power. It's essential to establish independent oversight and advice to ensure accountability.



e) Source and fund expert advice from outside the sector:
This process of change *must* draw on relevant expertise from outside the current mental health sector. This should include expertise from consumer perspectives, sexual violence prevention, expert trauma practitioners and academics, safety in institutional settings and systemic culture change experts.

Sexual violence has been an issue in the sector for at least 25 years—we have to accept that if the sector had the expertise to get this right they would have done it already.

- f) **Commit to a dramatic improvement in transparent reporting.** Reporting across the mental health sector requires dramatic improvement—but it is particularly critical for harms as serious as sexual violence. We call for public reporting of sexual violence to make this issue, and the progress of change, highly visible. This includes a commitment to ongoing, public, thorough and transparent reporting on sexual violence and safety, broken down by individual service, and beginning from this year's next DHHS Mental Health Services Annual Report.
- g) Commit to a long-term plan to successfully implement trauma-informed practice: We call for a commitment to realistic, long-term planning for implementing trauma-informed practice. Genuine trauma-informed practice will require at least five to ten years to implement successfully, partly because it involves pre-requisites that are major projects in themselves (eg, compulsory treatment and restrictive practices are contra-indicated for trauma-informed practice).
- h) Commit necessary funds, and a mandated requirement, for <u>all</u> staff, including psychiatrists, to be part of the change. Too often, psychiatrists are not part of training and change projects—apparently because the cost of releasing them from work is too high. Ensure that change involves all disciplines, including medical staff, and that learning programs are comprehensive, ongoing and embedded into basic qualifications, orientation programs, and include advanced levels, assessments, and evaluation of impact.

## PART B: Recommendations beyond 'The Right to be Safe' report

VMIAC has a different remit to the Mental Health Complaints Commissioner, and so we have some additional recommendations that go beyond the scope of 'The Right to be Safe' report. These are based in what consumers have told us clearly and passionately about sexual violence in hospitals.

## An acknowledgement and apology

We call for government to work with consumers to develop an acknowledgement and apology to the many people who have, over decades, been sexually assaulted, sexually harassed, or made to feel sexually unsafe, while in mental health services, and have often not been believed, supported, made safe, or been able to access justice. We've spoken with women who are still struggling with traumatic impacts, decades after being assaulted in hospital, and no-one has ever believed or acknowledged them.

## 4. Response for historical survivors

VMIAC has recently received a small, one-year grant to provide a pilot response to historical survivors of sexual violence in hospitals. We welcome this funding, but seek a commitment to:

- Ensure ongoing funding based on the emerging need
- Increase funding to sexual assault services and ensure access pathways for mental health consumers

## Address risks from staff

- Develop transparent processes and reporting for staff perpetrators of sexual violence
- Develop clear guidelines about staff negligence in relation to preventing sexual violence



## Immediate, urgent actions to prevent sexual violence

We call for a commitment to mandate the following urgent actions at every public hospital mental health service

## Urgent measure #1 Bedroom & bathroom locks WITHIN 3 MONTHS

- Conduct a rapid audit of installed & functioning consumer-controlled locks for every bedroom and bathroom door in every mental health ward. Provide immediate funding to install and/or repair locks on all doors.
- Commit to an annual, publicly reported audit of these locks, with an expectation of 99% doors with functioning locks. People deserve government confirmation, by year's end, that 99% of all rooms are safe.

## Urgent measure #2 New measures to make High Dependency Units safer

- No person must ever be locked into a high dependency / intensive care unit (HDU) for reasons of sexual vulnerability. Safer and more respectful approaches must always be used instead (eg, one-to-one nursing or a personal duress alarm).
- Unsafe HDUs<sup>16</sup> must be made single-gender.

## Urgent measure #3 Make women-only areas genuinely women-only

- Existing women-only areas must not be permitted to admit men, regardless of the impact on admission rates, with the only exception being people of non-binary gender who are assessed as presenting no risk.
- Provide public reporting on the availability of women-only spaces in units across the state, at each hospital and state-wide (see the background section for more information on reporting).

of sexual violence complaints relate to bedrooms

of sexual violence complaints relate to High Dependency Units

of sexual
violence
complaints
relate to
women-only
areas

## Urgent measure #4 At least 3 women-only units opened WITHIN 6-12 MONTHS

• Open at least three women's only mental health units within 12 months, including two metropolitan services and one regional service.

## Urgent measure #5

#### Ensure staff are supporting people to be safe

- All people, on admission, or as soon as practically possible, are:
  - Shown how to lock doors, and are provided support by staff to do so
  - Asked what would help them to feel sexually safe during their admission, and then supported to have those needs met (eg, a specific gender nurse, or options to modify bed checks at night)
- Give clear advice to services and professional bodies that, given the well-known risk of sexual violence, it is negligent for any staff member to discourage people from locking doors, or to leave consumer-locked doors unlocked (ie, after bed checks at night).

## Urgent measure #6

## Immediate responses to sexual violence

People experiencing sexual harassment or assault must be provided:

- The opportunity to transfer to a different hospital, if wanted, during the current admission
- A change of catchment area for future admissions, if wanted
- A free, independent counselling service if wanted, including support with making reports to police if wanted (we do not support mandatory reporting to the police for adult survivors)
- The choice (for adults) of whether or not to report harassment or assault to (a) police and (b) family or carers

<sup>&</sup>lt;sup>16</sup> We define 'unsafe HDUs' as: (a) HDUs that have shared bedrooms, or single bedrooms without locks, or bathrooms without locks, or (b) HDUs where sexual harassment or assault has occurred within the past two years.



# Clara's story

I was first forcibly locked up in a psych ward 4 years ago as a woman in my mid-20s. In the psych wards I met many lovely patients.... Yet a few patients frightened me by their highly sexualised behaviour; I immediately felt vulnerable to sexual assault. Each admission I can recall incidences of men coming up to me and commenting on my body, flirting and talking to me in a sexual manner.

I told my treating team this. I was always told I was safe in the ward and if I was anxious they would put me on anti-anxiety medication.

bedroom door, which they could have done because there were locks on bedroom doors. However, in the morning I always found my bedroom doors unlocked....

I was scared at night.

I would ask nursing staff to lock my

I was not allowed to have a phone. One male nurse thought I was scar was secretly hiding one. Alone, in my single bedroom, he used his hands to search me, touching my entire body, including my private areas.

He kept saying to me he was 'trying to find the phone'. I began to cry out and push him away from my body. But he was bigger than me.... And he just got more aggressive. He got my arms and pulled them behind my body and upwards....

Afterwards I remained in the corner of the bedroom for hours, frozen in fear and shock. The nurses didn't talk to me, or help me to move out of the corner. No one even asked me if I was OK for the rest of the night. I was sore and carried bruises for days from this nurses' assault.



One night in the high dependency unit another patient came in as I was lying in bed.... He knelt by my bed and said he wanted to watch me sleep.

I felt frozen in fear. After about 10 minutes of this he crawled on top of me, in my bed. His weight hurt me. He wrapped his arms around me like he was holding me. I thought he was going to rape me. I prayed I wouldn't get pregnant.

It didn't occur to me to yell for help. Although now I believe staff would have come to my assistance, something had changed in me; I had lost my fighting spirit. I thought the system too, was as dangerous as any troubled patient.

The next day, distressed, I absconded from the ward. I walked, without shoes, for three hours.

I was picked up by the police.... handcuffed ... and driven back to the psych ward.

It has been 2 years since I've been to the psych ward.

Since my psych ward stays I have had to spend time with a therapist talking about the terrifying things that happened to me on the psych wards. I had to pay for this therapy.

I have also developed a need to sleep in my own bedroom, and can no longer sleep in the same room as my wonderful partner; I just want to be alone.



## **BACKGROUND**

The recent report by Victoria's Mental Health Complaints Commissioner, 'The Right to be Safe', confirms that sexual assault, sexual harassment, and not feeling safe, have not abated, and that past efforts by government and the sector have failed.

Sexual violence can be devastating no matter when or where it occurs, however in a mental health service there are two tragic ironies:

- Most consumers are forcibly detained<sup>1</sup> in mental health services, supposedly to protect our safety—yet clearly this is not true. An admission to a mental health unit is extremely unsafe for many people.
- Around 85% of the people using these services are already survivors of trauma<sup>17</sup>, with about two-thirds of consumers having experienced child abuse<sup>18</sup>.

Mental health services are forcing people go through the very same kind of violence that triggered mental health problems in the first place.

The Department's own Chief Psychiatrist service guideline on gender sensitivity and safety<sup>19</sup> states that:

'Prevalence rates for interpersonal abuse (sexual abuse during childhood and/or adulthood, child abuse and family violence) for women with mental health or AOD issues range between 49 and 90 per cent'

Many people live with lifelong impacts, including the trauma of sexual harassment and assault, fear of being forcibly readmitted to this dangerous place, and hopelessness about not feeling safe to ask for help.

## Sexual safety versus sexual violence

Some people may wonder why we are using the language of 'sexual violence' rather than 'sexual safety', which is currently the more common term. It's because people who have survived this experience asked us to. No-one has ever contacted us at VMIAC to say they experienced a lack of sexual safety. They ring us to say they were raped or harassed, or that they don't feel safe from sexual violence.

We discussed this language in more detail at a recent consumer consultation about the issue, and the clear consensus was that 'if we keep talking about sexual safety, we are minimising what is often a criminal and harmful act'. Yes, we need to create safety, but shouldn't this be the default? Violence is the issue, and as uncomfortable as it may be to name, it's worse for the people who have to survive it.

<sup>&</sup>lt;sup>17</sup> Goodman, L.A., Salyers, M.P., Mueser, K.T., Rosenberg, S.D., Swartz, M., Essock, S.M., Osher, F.C., Butterfield, M.I., and Swanson, J. (2001). *Recent victimization in women and men with severe mental illness: prevalence and correlates.* Journal of traumatic stress, 14:4, 615:632.

<sup>&</sup>lt;sup>18</sup> Read, J., Fink, P.J., Rudegeair, T., Felitti, V., and Whitfield, C.L. (2008). Child Maltreatment and Psychosis: A Return to a Genuinely Integrated Bio-Psychosocial Model. Clinical Schizophrenia & Related Psychoses.

Office of the Chief Psychiatrist. (2011). Service Guidelines on Gender Sensitivity & Safety: Promoting a Holistic approach to wellbeing. Mental Health, Drugs and Regions Division, Victorian Government, Department of Health, Melbourne. Retrieved from: https://www2.health.vic.gov.au/about/publications/policiesandguidelines/Service%20Guideline%20for%20Gender%20Sensitivity%20and%20Safety (page 10).

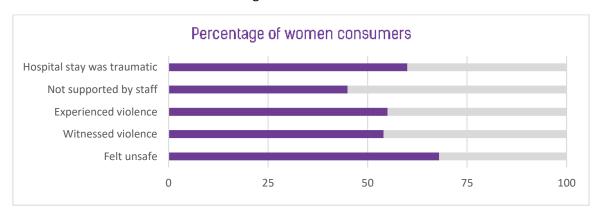


## Hidden harms and reporting

The issue of sexual violence in psychiatric hospitals has been known about for at least 25 years. In Victoria there have been multiple surveys and reports, the latest being 'The Right to be Safe' report by the Mental Health Complaints Commissioner (March 2018).

Despite all this knowledge, sexual violence is not a reporting category for services, and is not included in the department's annual report. This has to change. Hidden problems, particularly hidden violence, never resolves on its own. This issue needs a light shone on it, bright and focused, as a necessary strategy to drive change.

Because of the lack of reporting, we're unable to say how many people have experienced sexual violence while in a psychiatric service, however the Victorian Women's mental health service conducted a recent survey<sup>20</sup> of women consumers which revealed some alarming statistics:



The needs of men We note that this survey was only for women, yet 'The Right to be Safe Report' told us that about 20% of complaints were by men who experienced violence or didn't feel sexually safe. Despite our best efforts, VMIAC has not as yet been able to consult with men about this experience. We know that, regardless of setting, men may be less likely to come forward and speak about sexual violence: there are sometimes different and really difficult stigmatising beliefs that can get in the way. Because we have not spoken with men, we have not made recommendations about men's safety. However, we believe there is a clear need to conduct further research into men's experiences of sexual violence in hospital settings, and the factors that may create safety.

The needs of gender diverse people We are also mindful that people living with gender diversity may have particular needs which have not yet been fully understood or addressed, in relation to sexual violence in hospitals. We have consulted with only one person who identifies as transgender, who agreed with most of our recommendations but was concerned about women-only spaces. As with men, the safety needs of gender diverse people need much more attention and consideration.

The complication of catchment areas We are particularly mindful that the majority of people admitted to mental health wards are detained against their will, and that there is rarely a choice of catchment area, unlike other areas of health. This means that a person may be repeatedly detained in a place where they experienced sexual violence, which has obvious and serious repercussions for mental health outcomes. Because of the lack of reporting, it also means that people have no way of knowing how safe their local service might be.

Women's Mental Health Network Victoria. (2017). <u>Building in Safer and More Productive Outcomes for Consumers & Mental Health Workers: Key Findings of the Network's 2016 Hospital Experience Survey</u>.



## Concerns about implementing 'The Right to be Safe' report

#### **Concerns about Chief Psychiatrist Guidelines**

While VMIAC supports the principle of sector guidelines developed by the Chief Psychiatrist, in practice we have concerns with this approach. It is commonly known that many services do not comply with these guidelines, and worse, many clinicians are not even aware of some guidelines.

As a case in point, in 2011 the Chief Psychiatrist released a guideline on gender sensitivity and safety. This is a high quality paper, and even includes sections on trauma informed care and expectations of services and clinicians. Yet little, if any, of this content is applied in practice. As a consequence, we are unconvinced that another guideline will achieve any more change than the last one.

We strongly recommend that work be undertaken to identify why guidelines are often ignored, and what measures can be undertaken to improve the way that guidelines are developed, implemented, measured and complied with. Our view is that the sector's continued lack of compliance with guidelines is a serious safety issue in many areas of practice.

In the meantime, we recommend that any directions given to the sector about this issue must be much more impactful than guidelines. This may take the form of Chief Psychiatrist Directives, a Code of Practice, or other forms of mandated action for which services must be transparently accountable.

It is important to remember that documents do not keep people safe, nor do they drive change. Action does that.

#### **Concerns about change mechanisms**

Many change projects in the mental health sector are delivered following a similar process, which looks something like this:

- Form a committee with government, many representatives from the sector, and 1-3 consumers and carers
- Develop a framework document and/or some guidelines
- Develop a short training course
- Roll out the training, with attendance mostly by allied health and a subset of nurses. Few, if any, psychiatrists participate
- Perhaps provide some resources, like posters or cards to go in staff lanyards
- Perhaps do a short-term evaluation
- End the project

On the surface this process makes sense, and perhaps it works in some instances—but in many instances it fails to create real, lasting change. Just some of the issues with this include:

- Closed loop: rarely are new ideas brought in to address the problem, and people 'don't know what they don't know'
- Documents don't do anything on their own: There are a lot of documents in the mental health sector.
   There are nowhere near as many mandated requirements, checks and balances, reports, audits or deeply engaging implementation activity
- Snapshot change: One off training may make some difference at the time, but this sector has significant turn-over, and within a year there will be many staff with no knowledge or skills on the matter.
- Superficial change: Short training courses may be suitable for learning a simple applied skill, like using a software package, or infection control procedures. They are questionably effective at driving attitudinal and culture change, or for learning highly complex interpersonal skills.
- Optional change: Many of the change projects in Victoria have an almost 'optional' flavour, and it's not difficult for a service to take a little bit of action then get back to 'business as usual'.



We urge that a different approach is taken for addressing sexual violence, and our call to action includes some recommendations to start to shift our thinking.

#### **Concerns about risk assessments**

The mental health clinical sector already relies on many different risk assessments – yet these have repeatedly been demonstrated as unreliable, and even unsafe when they create a false sense of confidence. Victoria's Chief Psychiatrist recently held a forum which made clear that risk assessments do not have a strong evidence base. And as consumers, we know that they already result in staff spending more time filling out paperwork than spending face-to-face time with us, getting to know our needs and providing support.

While we acknowledge the need to try and asses the risk of perpetrating sexual violence, and the risk of sexual vulnerability, we are not convinced that another risk assessment process or form will achieve this end. We advise thoughtful evaluation of this recommendation, and the consideration of alternatives, such as improving therapeutic connection, having conversations about trauma, sexual activity and sexual violence, and open conversations about sexual safety on a unit.

In particular, we would advise an approach where the clinician supports the person to identify risks, necessary supports and risk management options themselves.

### Reflections on past efforts by government

We acknowledge there have in the past been some efforts by government to address sexual violence in mental health services—but these have been fragmented, ineffective, insufficient, and lack basic quality processes. For example:

2009

The Office of the Chief Psychiatrist released a guideline: <u>Promoting sexual</u> safety, responding to sexual activity, and managing allegations of sexual assault in adult acute inpatient units.



The Office of the Chief Psychiatrist released a guideline: <u>Gender sensitivity</u> and safety



The previous Victorian government ran a 'Safety of Women in Mental Health Care' initiative, funding \$6 million to improve the safety of women in mental health services. This appears to be the largest investment in addressing sexual violence in mental health services to date, yet it was not successful. This needs to be well understood in future efforts.

These are some of our questions about the initiative:

- Why wasn't funding provided to all services? It appears that only some services could apply for funding, and it was up to them to decide what the local need was. There was no mandated minimum standard to ensure sexual safety.
- Why was there never an audit process to determine how many people had access to a lockable bedroom and bathroom, or women's only corridor?
- Why was there never an ongoing process to ensure maintenance (anecdotally, today many of these locks are broken) or staff procedures (consumers tell us that many staff unlock bedroom doors during night rounds)
- Why wasn't incident reporting addressed?



• Why was there no follow-up process to assess the impact of these changes on safety, and to ensure continuous improvements to safety over time?



Chief Psychiatrist implements a pilot reporting processes for sexual safety.

Current Victorian Government releases its Gender Equality budget statement. The section on Safety and freedom from gender-based violence. There are no initiatives or funding for sexual violence in mental

health services. Worse, the Gender Equality Budget Statement (2018) suggests that the newly budgeted \$119.2 million for mental health services will help ensure gender equality in health services, when it fact it appears to be funding more services where people will be at risk of gender based and sexual violence.

## When staff are perpetrators or negligent

Twenty-two percent of complaints investigated in *The Right to be Safe* report were about the behaviours of staff. Regarding complaints about staff, the report says:

'The majority of perpetrators were described as other consumers (77 per cent, n = 65 of 85), which, as noted earlier, is the focus of this report. This is not to understate in any way the seriousness of complaints relating to staff, which included complaints about the conduct of clinical staff and security personnel, as such alleged conduct represents potential misconduct and/or criminal offences. There are, however, clear requirements and processes for addressing alleged conduct issues of staff...' (page 56).

While it may be true that separate processes exist for staff who are perpetrators of sexual harassment or assault, what consumers tell us is that:

- There is no transparent accountability for staff who breach sexual safety in a non-criminal way, ie., unprofessional actions or negligence such as failing to re-lock a bedroom door after performing bed checks during the night, or telling consumers not to lock their doors because it's 'inconvenient for staff'
- There is no clear accountability for staff who fail to respond to sexual violence in a professional manner, ie, disbelieving the person, not providing support, not creating safety, not reporting to police when requested.
- When staff perpetrate sexual harassment or assault, there is no way for consumers to know whether these staff have faced either professional or criminal consequences

Significant work is required to define professional, unprofessional and negligent conduct in relation to sexual safety in mental health services. Many consumers of the clinical mental health sector have already survived abuse in institutions and are not likely to have faith that professional bodies, the justice system or the department will hold perpetrators to account.

The Royal Commission into Institutional Responses to Child Sexual Abuse made it very clear that large institutions typically do not hold staff accountable for abuse, particularly when these institutions can keep responses hidden. Why would the mental health system be any different? Regardless of how many good people work in the system, any system this large, with this much power, will have perpetrators and avoidance within it somewhere.

The mental health sector needs a transparent, high level report on staff perpetrators, so that consumers can have confidence that they will be safe on a future admission, and that staff have not just been transferred to a different service. This work needs to be undertaken in partnership with consumers, and with regard to the findings of the Royal Commission.



**POSITION** 

3



# CASUALTIES IN THE COMMUNITY

Thousands of distressed Victorians have been locked out of community support since the NDIS rollout





# Casualties in the community

# THE ISSUE

Victoria has used the NDIS as an excuse to cut vital services, and created casualties in our community of people who desperately need support.

Consumers have lost most of the non-clinical services we used to have. We were told the NDIS would be there for us instead—but it's not.

- Most of us are not even eligible
- Even when we're eligible, trying to get in is too hard
- And if we do get in, many don't get much of a service anyway

The NDIS was never meant to replace this community sector—and it hasn't. People need good quality, mainstream services that provide support, habilitation and rehabilitation, all with a focus on recovery. Access to these kinds of services will mean most people will never need something like the NDIS.

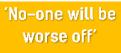
Back in 2013, Victoria decided to cut funding for rehabilitation (and habilitation)
services—and redirect almost all this funding to the NDIS during the years of NDIS rollout. Rehabilitation
services are related to, but more comprehensive, than support services. This has dramatically reduced the
quality of the few remaining community services. Over the last five years, people have lost access to more and
more services. Habilitation and rehabilitation services are not just 'nice things to have'—they are human rights
protected by the Convention on the Rights of Persons with Disability (CRPD), ratified by Australia.

Today, with dwindling community support and little NDIS access, increasingly people are forced to go to hospital—which is restrictive and scary for us, and very expensive for government. We were told no-one would be worse off. It's not true. This is terrible public policy.

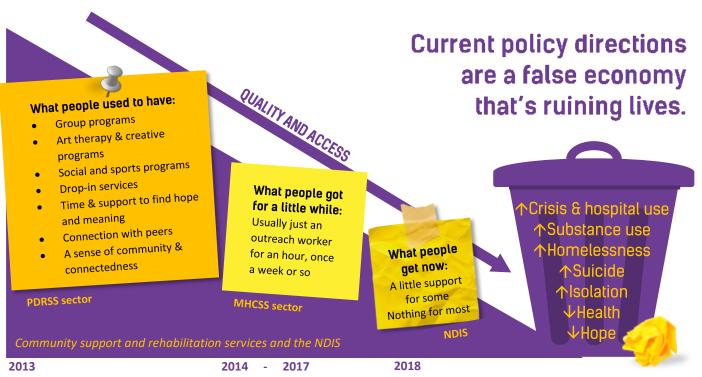


'People will get choice & control'











# **VMIAC'S POSITION**

- 1. Every person who requires support, habilitation or rehabilitation services in Victoria should be entitled to receive them. In particular, these should be available for all people at risk of hospitalisation or suicide, or who have already been hospitalised for mental health reasons.
- 2. The Victorian Government has a universal service obligation to ensure provision of support, habilitation and rehabilitation mental health services—separate to the NDIS. These services are not just for people with lifelong disability, they aim to prevent lifelong disability and promote recovery. This is consistent with
  - NDIS principles agreed by COAG (2015)
  - Convention on the Rights of Persons with Disability (UN, 2006)
- NDIS Act (Aust, 2013)
- Charter of Human Rights & Responsibilities (Vic, 2006)
- 3. The Victorian Government failure to fund access to support, habilitation and rehabilitation has a discriminatory effect on people being able to exercise their rights across many aspects of life.
- Access to any mental health service must be encouraging, supportive, straightforward, timely and inclusive—not adversarial, traumatising, overwhelming, lengthy and discriminatory.
- 5. High quality support, habilitation and rehabilitation services must include group programs, centre-based programs, drop-in services, arts programs, counselling, and more. Outreach services alone are insufficient and leave people unsupported and isolated.
- 6. The NDIS is performing poorly for people with psychosocial disability. The Victorian government has a responsibility to hold the Commonwealth government to account for failing to deliver a safe and quality service.
- 7. The NDIS legislative requirement for permanent functional impairments remains unacceptable and unworkable for people with psychosocial disability. Despite reassurances to the contrary, this concept is used in a discriminatory manner for people with psychosocial disability, and prevents genuine recovery.



# **OUR CALL TO ACTION**

We call on political candidates and parties to commit to:

1. Hold the Commonwealth government accountable for NDIS failings

NOW

Victoria committed millions of dollars to introduce this scheme to Victoria, and we signed a bilateral agreement with the Commonwealth Government to get a quality service for the people of this state. The NDIS promise has not been fulfilled, so it's time for Victorian politicians to hold the Commonwealth to account. Just like any other purchase with a contract, we need to ensure that Victorian citizens get what we paid for.

2. Fund a new kind of service: 'Walk-in community support'

WITHIN 6
MONTHS

Consumers have told us very clearly that drop-in services are one of the things they miss the most. Good quality drop-in services provided a space where anyone was welcome, and where people felt safe amongst their own consumer community.

We acknowledge that, in the past, these centres were not always well-managed, but the good ones were outstanding and nothing since has come close to meeting our community's needs. To prevent problems of the past, we recommend taking the best of previous drop-in services to design a new, non-clinical service system called 'Walk-In Community Support'. We recommend new funding is dedicated to establish walk-in services which provide:

- A service in every catchment area
- Easy 'walk in' access
- Peer support, counselling, support work, habilitation and rehabilitation programs
- A range of group programs
- Emergency assistance
- Connection with peer community
- Specialist supports and referrals for substance use, trauma, housing, emotional distress
- Women-only areas or times
- Practical facilities like shower or laundry access

#### Fund VMIAC to provide an independent advocacy and peer support to people struggling to access the NDIS

WITHIN 6
MONTHS

It is simply too hard for many people with psychosocial disability to get into the NDIS. The access process is often discriminatory and damaging to people's mental and emotional health. Sometimes, community sector workers have assisted consumers through this process, but as defunding continues, we are seeing less consumers able to access advocacy or support.

We seek funding to provide a peer support and advocacy service for Victorian consumers who need significant help to access the scheme, gather 'evidence', work through planning their support needs, keep and maintain their plans, and get started with their package.

This will prevent many of the issues we currently see, such as:

- People who most need support giving up because it's too hard for them
- People who can't articulate goals (because of their disability) not being able to get support



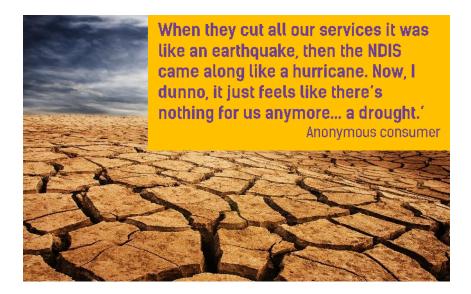
- Emotional trauma from the access process (we can provide validating support and empathy throughout a difficult process)
- Consumers making common errors while trying to navigate the NDIS bureaucracy
- People receiving a plan but never activating it, because they don't know how. We know of many
  people whose funding is sitting with providers, but they're not getting a service
- Fund a coproduced project to understand and address widespread support, habilitation and rehabilitation gaps for consumers following 5 years of disruptive sector change

WITHIN 12 MONTHS

Many parties are advocating substantial funding back into the community mental health sector. We have a different view. While we agree that Victoria needs a strong and well-funded non-clinical community sector, we know that there has also been unrivalled disruption to this sector over the past 5 years which necessitates a rethink of what this actually means:

- Since the 2013 state government 'reform' from the 'PDRSS' sector to the 'MHCSS' sector, consumers report a dramatic decrease in quality and range of support services. The baseline service of the past five years is not good enough—we need to redefine basic standards of quality community services
- Since transitioning to the NDIS, much of the community sector workforce has left the sector.
   Providing new funding may not be enough to bring these people back—new funding will also require a workforce strategy
- Most major papers examining the impact of NDIS and community mental health services all cite
  different figures. We need much greater clarity about how many people actually need support, how
  many have it, and how many do not have it
- Primary Health Networks are playing an increasing role in community mental health which varies by area, and is not clearly defined in relation to other parts of the sector
- In 2013 the community sector funding changed from 'rehabilitation and support' services to 'support services' only. Now there are no services which provide rehabilitation (or habilitation) services for mental health related needs—yet habilitation and rehabilitation are a right under the CRPD

We ask for a commitment to coproduce<sup>21</sup> a large-scale investigation into the gaps and needs, a process to design service quality and demand, and then determine the cost. This is not a project that a consulting firm can conduct alone, but requires deep involvement by many consumers, workers from past and current sector models, NDIS practitioners, academics and other stakeholders.



<sup>&</sup>lt;sup>21</sup> Co-Production means that you work with us, the consumers/recipients of the service, as equal partners in defining the problem/need, designing the solution, and producing and delivering the end product. As consumers we have valuable wisdom about what works and what doesn't, and we have none of the conflicting interests of the sector in maintaining a power base or income stream. Our only interest is to ensure high quality, safe, rights-based services.



# **BACKGROUND**

## Why do people need support?

A lot of people don't understand the support needs of people with more extreme experiences of mental and emotional distress. Some may even think that we get all the support we need from hospital services, but this is far from true.

#### Hospitals don't provide therapy, support or rehabilitation

- Hospital treatments for mental health are almost exclusively about providing control, medication and electro-convulsive therapy (ECT, or shock treatment), usually over a 9-day admission.
- Most people are forcibly detained and treated against their will, so it is often experienced as more traumatic than helpful.
- Hardly anyone receives psychological therapies or counselling—even though the majority of consumers in these services have a history of complex trauma and abuse that is related to their mental health problems.
- Even if hospitals wanted to provide rehabilitation services, it would be
  unlikely to work. Psychosocial rehabilitation services require a high degree
  of trust and repport, and this is almost impossible in a service where the use
  of compulsion is so common.

People don't leave a psychiatric hospital services feeling healed and supported.

In fact, people are about 100 times *more* likely to die by suicide after a psychiatric hospital admission, found a recent meta-analysis of 50 years of psychiatric research.

Hospitals provide an intensive, usually forced, response to a crisis, with medical interventions. There's always lots of demand for beds, so as soon as they think we're safe, we get discharged. They don't support people to make sense of what's happened, process the experience, or to recover and heal.

Read more about what people do an don't receive in Section 1: Hurt in hospitals.

# Support, habilitation and rehabilitation

Most people understand rehabilitation in relation to a physical injury. But people get confused about rehabilitation for mental and emotional health problems. The broad principles are the same:

Skills Knowledge Learning

Empathy Connection Supportive **Habilitation**<sup>23</sup>: Supports people to *attain*, keep or improve skills and functioning **Rehabilitation**<sup>2</sup>: Supports people to *re-gain* skills, abilities, or knowledge that may have been lost or compromised as a result of acquiring a disability

**Support services:** Mental, emotional, social and practical support to fully participate in life. This includes supportive listening, helping people reduce social isolation and gain a sense of community belonging, and providing empathy and encouragement.

#### Our recovery needs

The experience of having extreme mental and emotional distress can be devastating. We know from research that it is common for people to need many of these kinds of assistance from mainstream services:

- Support to gain hope and reasons for living
- Having places where we feel accepted for who we are, 'places of belonging'

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<sup>&</sup>lt;sup>22</sup> Chung, T., Ryan, C.J., Hadzi-Pavlovic, D., et al. (2017). <u>Suicide Rates After Discharge From Psychiatric Facilities: A Systematic Review and Meta-analysis</u>, JAMA Psychiatry, 74(7):694-702.

<sup>&</sup>lt;sup>23</sup> Habilitation and rehabilitation are not just 'nice to have'. For people with a psychosocial disability, they are a human right, enshrined in Article 26 of the United Nations Convention on the Rights of Persons with Disability (CRPD, 2006).



- Support to build or rebuild confidence in themselves
- Help to connect with friends, family and communities and not be isolated
- · Support to build or rebuild our identity as someone of worth and value, beyond our diagnosis
- Supportive spaces to process the trauma of forced treatment and detention
- Supportive space to disclose and begin to process initial trauma. There are strong links between past trauma and mental health experiences which are rarely, if ever, addressed by clinical services
- Practical help to get their lives on track, including housing, employment, parenting, managing finances, transportation, self-care
- Time and information to understand the full implications of mental health problems
- Developing coping skills and strategies
- Programs and supports to build or rebuild life skills, make sense of experiences, and move towards recovery
- Programs and supports to address life expectency issues, including understanding and living with the risky side effects of psychiatric medications
- Support to prepare advance statements in case of future hospital admissions
- Accessing other needed services

Most people with serious mental and emotional health problems have these needs, regardless of whether they have a 'permanent disability'. And state governments are responsible for providing these services, not the NDIS.

We would argue that one of the main reasons for high hospital readmission rates is because people are not able to access these kinds of support services (and that hospital services are increasingly unfit for purpose).

## Habilitation and rehabilitation will never be provided by the NDIS

The NDIS cannot and will not provide habilitation or rehabilitation services: the agency has been consistently clear that these are the responsibility of 'mainstream' services, in other words, the Victorian Government.

# Why does the Commonwealth and NDIS need to be held accountable?

# Discriminatory processes for psychosocial disability

1. Trying to access the NDIS can worsen people's mental and emotional health

People with psychosocial disability are facing discriminatory access barriers, and worse, some people end up with more mental and emotional distress as a consequence of trying to access the scheme. Having a psychosocial disability means that people have emotional and cognitive barriers to participation, yet the NDIS access process includes lots of emotional and cognitive barriers: it is often experienced as hurtful, frightening, and very complex.

I have found the process of transitioning to the NDIS to be inherently re-traumatising, even though I was in a defined program.

And observing my peers (who needed to apply) being treated so badly within a system riddled with catch 22s is heartbreaking.

Krister

We all understand that it's discriminatory not to provide wheelchair ramps for people with impaired mobility. These ramps mean that people with disability can access the places they need to go. For people with a psychosocial disability, our version of a wheelchair ramp includes:

- Respectful and emotionally supportive communication and messages
- Simplified processes, and support to navigate complex processes
- A range of communication methods (many of us can't use telephones or post)



- Collaborative (not adversarial) review and appeal processes
- Supported decision making processes, including advocates and access to our peers

# 2. Some people with the greatest need are excluded: because NDIS does not understand how goals work for people with psychosocial disability

Another critical discriminatory issue with the NDIS is the requirement for a person to state their goals up front. This is fine for some of us, but for most people with psychosocial disability this is impossible—precisely because of our disability. A lack of goals is not a sign that someone doesn't need support—it's the complete opposite. For example, it is nonsensicial and unhelpful to ask a person who lives with constant suicidal voices about their goals for the future, and then deny support if they can't articulate any goals. It is our strong view that people who are unable to articulate goals are precisely the people who most need large support plans, often beginning with comprehensive access to therapy or counselling to overcome these barriers to functioning.

#### 3. Unfair cuts after receiving access, risks to health & life expectancy

We are increasingly hearing from consumers accepted into the NDIS, who are then required to attend an unscheduled review of their package.

At these unscheduled reviews, people's previously approved supports are removed. Some people have lost access to programs like art therapy and other therapies, while we have heard multiple cases of people losing support for gym membership, with comments made by NDIA staff like 'well, everyone wants a gym membership'.

Actually, people with psychosocial disability often have morbid obesity combined with excess sedation and metabolic disorders—all as side effects from psychiatric treatments. These conditions can cause extreme limitations to daily functioning, and can be exceptionally difficult to address without support. This is one of the reasons people with a psychosocial disability have a 20 year reduced life expectancy—and NDIS cutbacks like these are increasing the health risks for people.

# Risky requirements while 'playing the bureaucratic game'

The NDIS asks people to prove that they've exhausted all health treatments, before accepting that a person has a permanent disability. Of course, this is nonsense for psychosocial disability because there is no evidence about permanence for any mental illness diagnosis. Some psychosocial disability is permanent, some is not, and there is absolutely no way to reliably predict which is which. But consumers and health workers are expected to play this bureaucratic 'game'.

Some consumers have told us about concerning advice by NDIA staff about what they have to do in order to be found eligible, for example:

- To try electroconvulsive therapy (even though it has a poor evidence base for many conditions, and carries a risk of memory loss and cognitive impairment)
- To try all of the different psychiatric medications (even though many of these carry serious health risks and may even cause new, permanent disability, such as tardive dyskinesia)
- To agree to previously ordered compulsory treatment that the person has appealed and won in the Mental Health Tribunal

#### This is concerning because:

- NDIA staff are not health professionals, so why are they giving medical advice?
- Desperate people are taking risks they wouldn't otherwise take



- The right to access support is not supposed to be dependent on such unreasonable conditions
- Consumers already experience too many rights violations related to treatment in health services. It is
  cruel and unnecessary to extend this to support services. Further, the NDIS was intended to increase
  Australia's compliance with the CRPD, not worsen it.
- The NDIS is acting as though psychiatric treatments have the same kind of evidence base as treatments in physical health. This is simply not true. Most psychiatric treatments have disputable evidence at best.

### Other barriers for people with psychosocial disability

#### A history of trauma makes it less likely to get support.

Our interactions with the NDIA suggest that their way of thinking about psychosocial disability is even more medicalised than psychiatric services. It is already clear that if people talk about past trauma or abuse, that they are less likely to gain access to the NDIS than if they talk about having a biological illness. This is nonsensical because the vast majority of people with psychosocial disability have a history of profound trauma.<sup>9,11</sup>

#### Access for episodic conditions is not happening.

We were told that people with 'episodic' conditions could still access the NDIS, but this is providing to be untrue. In practice, this only happens if people can prove that, even between 'episodes' of extreme distress, they still have a substantially reduced functioning. This is simply not practical or realistic for many people. It creates enormous risks for those people if and when they become unwell—particularly with the increasing lack of any other support services.



# **GETTING INVOLVED**

Do you want to get involved with our campaign?

## Coming soon

- Tell your story about why these issues matter—we'll be holding an event soon for consumers to come in and tell their story in a way that works for you (written, artwork, video) then sharing our stories as part of the campaign.
- Campaigning tips and templates for consumers, to help raise the issues with local election candidates

#### Closer to the election

- VMIAC election forum for consumers and supporters: Hear more about the issues, how the major parties are responding, and what others are up to: Save the date for 24<sup>th</sup> October 2018.
- VMIAC will publish reviews of mental health-related campaign policies and promises, to help consumers make sense of all the different election hype.
- As we get close to election day, VMIAC will publish an election scorecard (from consumer perspective) about all the major parties, on all the major issues that matter to us

# **Hurt in hospitals**

Sexual violence in hospital

Let's make it matter.

# Casualties in the community

# Stay in touch and up to date

- Like us on <u>Facebook</u>
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- Become a VMIAC member (it's free!): Join here
- Visit our election web page for all the info: www.vmiac.org.au/election-18