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Chair: Judi Burstyner [redacted]

Thank you for the opportunity to present the views of ISFAF members to the Royal Commission on Mental Health,

1. PREVENTION, RECOVERY AND 'OTHER SERVICES'

How to most effectively prevent mental illness and suicide

The expression of genetic susceptibility to mental illness is associated with social factors including trauma, family violence, poverty, unemployment, gambling, tobacco, alcohol and drug use (AOD). These are major social problems which need to be addressed to reduce mental illness in our community.

The association between gambling and mental illness is less readily known than the association with AOD, but a strong association has been shown between all three[1], with the association between gambling and mental illness ranging between 100% and 56% depending on the psychiatric diagnosis.[2]
The increase per capita of drug, alcohol, mental health issues and suicides indicates that avenues of prevention must be substantially increased. These avenues include:

- Education of community from primary school to adulthood on the dangers of AOD and gambling, including:
  - healthy diet as a way of life – tuck shops to eliminate sugary / fat foods,
  - physical exercise as a way of life,
  - positive rather than negative education,
  - minimizing screen time,
  - outdoor education,
  - healthy after school programmes,
  - contribution to community programmes to help the underprivileged,
  - mentoring,
  - programmes to increase self-esteem, self-efficacy, 'making good choices',
  - programmes on good parenting
- Education of school staff, community leaders, sporting associations, primary care providers to help them recognize and manage those at risk – with suitable service promptly available for those at risk to be cared for… no long waiting lists
- Reduced access to illegal substances – including during school years,
- Improved social conditions - reduced unemployment, poverty, family violence, improved access to safe affordable housing,
- Early intervention and prompt access to appropriate care before addictions take hold.

Best practice: Care models providing safe, person-centred continuity of care when possible.

Many mental illnesses are episodic but because of the deeply personal nature of psychosocial issues and the need to establish trusting relationships with clinicians, carers and consumers expressed their need for continuity of care across lifespan, location and symptoms. [3] Continuity of care may provide a means by

[1] Polenza M.N., Fiellin D.A., Heninger G. R., Rounsaville B.J., Mazure C.M., (2002) Gambling An Addictive Behavior with Health and Primary Care Implications *J.Gen. Intern Med* 17(9):721-732
[2] Cunningham-Williams R.M., Cottler L.B., Compton W. M., SlitznagelE.I., Ben-Abdallah A. (2000) Problem gambling and comorbid psychiatric and substance abuse disorders among drug users recruited from drug treatment settings and the community. *J Gambl Stud* 16:347-76
[3] Alfred Mental and Addiction Health: Carer and Consumer Workshop 2 July 2019.

which individuals facing stress and the consequent strain on their mental health have a professional to turn to. This strategy may reduce the likelihood of a relapse, thereby assisting both the individual at risk and reducing the cost of high level mental health care to the community.

Case Study: M[redacted], a 39 year old professional was diagnosed with schizophrenia in his teens and has managed his mental health issues with a private Counsellor for two decades. From time to time, when he feels that his mental health is strained, he seeks assistance from the familiar team at a local private hospital. After a short time, he returns to work. The prompt availability of person centred care in familiar surroundings has sustained M[redacted] through successful tertiary study and two decades of 'a good life'.

2. DELIVERY

Where can we seek help acute crisis?

My experience of collaboration between police and psychiatric crisis teams (PACER… ?Police and Crisis Emergency Response) is excellent. But the scope of the service is inadequate.

The PACER service needs to be expanded in number, locations and to have 24/7 availability.

Homeless and Needing mental health care **[redacted] year old** **D[redacted] T[redacted]** [redacted]	[redacted] 2012: Case Study: The story of two D[redacted] • D[redacted] T[redacted] presented at [redacted] Emergency Department saying he felt (psychiatrically) unwell, • Turned away because assessed as being not sufficiently unwell, • Refused to leave, demanded help • Police were called – **our health services could offer only the police to a person asking for psychiatric help** • Police drove him to two shelters, none of which had room, • Police dropped him at corner of [redacted] and [redacted] Streets [redacted] • Two hours later, he was dead – stabbed to death on the sidewalk by [redacted]	**Homeless and Needing mental health care** **[redacted] year old** [redacted] Initially charged with T[redacted]'s murder, later reduced to manslaughter**,**

This case illustrates some reasons why many individuals with mental health challenges are denied their rightful place in society:

- homelessness, lack of safe accommodation both short and long-term
- lack of community mental health facilities:
  - The Victim: despite D[redacted] T[redacted]'s insight into his need for help, the psychiatric unit he knew turned him away because he was 'not sufficiently unwell' for the acute hospital care that they offered. **However, they had nowhere to refer him for appropriate care and their only recourse was to call the police, who couldn't even find him a safe place for the night ,**[4]

    The lack of appropriate facilities has not changed. 'Not sick enough' is a widespread response by mental health providers to a plea for help.[5] Members of Inner South Family and Friends (ISFAF) are regularly faced with the problem of their loved one being turned away from the emergency department of a psychiatric unit in a major hospital. Such refusal invariably results in deterioration to crisis point. This results in prolonged hospitalization, increased (expensive) medication and lack of long-term hope. It used to be known as the 'Revolving Door', but in

    July 2019 I heard a patient referring to herself as being in the 'Recycle Bin'. …. What horror has our society provided for a human to see oneself in those terms as a result of 'health care'?

    No wonder they suicide.

[4] [redacted]

[5] Olasji, M., Maude, P., McCauley, K., (2017) Not Sick Enough: Experience of carers of people with mental health illness negotiating care for their relatives with mental health services. *J. Psychiatr Mental Health Nurs.*, (24)403-411

- The Killer: [redacted] was able to kill D[redacted] T[redacted] despite having previously stabbed a random person multiple times in [redacted] while on 'ice', completing a three year sentence and release from jail with the same drug addiction that he had entered with. His continued addiction and the availability of ice enabled him to repeat his earlier behaviour by stabbing D[redacted] T[redacted] 12 times.[6] [redacted]'s story illustrates the need to:
  - improve drug and alcohol prevention and treatment in society,
  - improve rehabilitation within the penal system,
  - provide person centred assistance and follow-up after release from jail,
  - reduce the availability of illegal drugs and the 'ice' (crystal methamphetamine) epidemic.

We lack community based mental health care.[7]

General practitioners (GPs) are overworked, busy, often poorly educated in mental health but swamped with material from pharmaceutical companies. In the USA, reliance on material from pharmaceutical companies is a major contributor to a major opioid epidemic. Australia has one of the highest use of anti-depressants per capita[8]. GPs rarely have the skill or time to devote to providing primary mental health care but they need greater education to know when to refer to specialist services.

The problem is that there are not enough, if any, specialist services either within the public or private sectors.

Community based services prevent escalation of distress to crisis level. Comprehensive Primary Health Care Services such Star Health[9] and Prahran Mission (Uniting VicTas)[10] need to be expanded to be able to service the demand in their area and to offer a wide range of integrated, continuing care. Such community services need to be promptly available to those in need in many locations. Long waiting lists lead to crisis and additional trauma and cost to the community.

The concept of Soteria,[11] providing a therapeutic residential environment to prevent of hospitalization for individuals experiencing psychosis, such as 'Dream Home',[12] Soteria Berne,[13] and others have been shown to be successful in reducing the need for hospitalization, reducing the need for medication (and thus reducing the untoward side-effects of medication).[14]

Availability of person centred hospital care for individuals in acute crisis

Individuals who require hospitalization are in psychological turmoil and need to feel safe, nurtured and cared for by staff who care about them.

However, many psychiatric admissions are traumatizing rather than therapeutic.

Modern perceptions of hospital care have improved yet at a top Melbourne psychiatric unit, hot water was unavailable for two weeks, forcing patients to shower in cold water during winter. Patients in a non-psychiatric unit are unlikely to have tolerated this and a milieu such as this is hardly therapeutic - especially for a cohort in which personal hygiene can be problematic.

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6 [redacted]

[redacted]

7 'Nothing between GP and emergency' https://www.theage.com.au/politics/victoria/nothing-between-gp-and-emergency-victoria-s-mental-health-failure-20190227-p510ip.html

8 Davey C.G. Chanen A.M., (2016) The unfulfilled promise of the antidepressant medications 204((9):348-350

9 Star Health: https://www.starhealth.org.au/

10 Prahran Mission: https://www.unitingprahran.org.au/

11 Soteria - https://en.wikipedia.org/wiki/Soteria_(psychiatric_treatment)

12 Dream Home Vermont: https://www.pathwaysvermont.org/what-we-do/our-programs/soteria/

13 Soteria Berne: https://www.igsbern.ch/de/index.php

14 Carlton t. Ferriter M., (2008) A Systematic Review of the Soteria Paradigm for the Treatment of People Diagnosed With Schizophrenia *Schizophr Bull* 34(1) 181-192.

Psychiatric in-patient units (IPUs) need to provide a therapeutic environment, including

- ensuring all patients feel safe at all times,
- having some female only areas,
- a staff member allotted to each patient to help them through the admission process and to make them feel a welcome, valued individual throughout their stay,
- psychological care once patient level of distress permits,
- specialized staff to assess, monitor and improve the general systemic health of each patient,
- providing a means of exercise for patients and specialized staff to work with patients to improve their physical health. This may include walking groups where possible as access to the outside prevents patients feeling isolated from 'the real world',
- indoor and covered outdoor relaxation areas,
- a relaxing pleasant ambience,
- activities such as art therapy, music therapy, games,
- areas where patients can spend undisturbed time with visitors,

and this cannot occur without adequate funding.

Trust to therapists having been established within IPUs, there needs to be continuity of care with the outside team to prevent individuals having to repeat their stories and feeling that the system regards them as a 'case' rather than a person.

Discharge, follow-up and community care

To prevent the all common 'revolving door' (?'recycle bin') of repeated hospital admission, discharge needs to be well timed – *i.e.* left till the patient is ready, rather than occurring because someone else needs a bed, or because it looks better on case-mix statistics.

Discharge must:

- be to safe accommodation suited to the individual's needs,
- be followed up. This as an opportunity for continuity of care and to ensure that the individual has adequate daily living skills, a social network, a primary health care network, trusted clinicians to whom to turn in times of need and activities in place,
- continued care needs to remain in place for an extended period – possibly for years – to avoid relapse.

The current situation, which lacks discharge to safe, suitable accommodation and does not provide adequate post discharge care, is a major factor in relapse and leads directly to increased use of hospitals, *i.e.* wasted funding unnecessary and suffering by consumers and carers.

Community Care needs to reinforce the above post-discharge strategies.

Mobile Support Teams (MSTs) and In-house Assistance can greatly reduce relapse and the need for hospitalization. Currently MST seems restricted to very severe need, but this excellent service need to be extended to all individuals who would benefit.

The extended use of in-house visits by clinicians has occurred with great success among services to the autistic and needs to be extended to individuals with mental illness and their carers.

Increase 'Talking Therapy' from Early Intervention and throughout Management to obtain greater Recovery and to reduce expensive medication and its side-effects

That individuals in distress need someone to talk to is not new.[15,16] Regrettably, the chemical revolution of the late 20th century, sidelined talking therapy. This has resulted in the explosion of pharmaceutical costs

[15] http://www.moshersoteria.com/

[16] https://en.wikipedia.org/wiki/The_Myth_of_Mental_Illness

and the dooming of many unfortunate individuals – consumers and carers alike - to a life-time of dependency on government support.

The biomedical model of mental 'illness,' which relies largely, and frequently entirely, on expensive pharmacological management of crises is not universally accepted.[17,18,19,,20,21,22,23] Many psychological crises are a call for help, a response to trauma. Addressing the biopsychosocial needs of individuals in crisis has been shown to improve outcomes with greater success and less cost than pharmacy[24],
e.g.
Open Dialogue (OD) Established in Western Lapland, in OD psychosis is seen in a family and network-centred context and generally managed in the consumer's home with the help of a multidisciplinary team. At five-year follow up after a major psychotic episode, 82% of individuals were symptom free, 86% had returned to studies or full-time work and only 14% were on disability support, with only 29% having used psychotropic medication at some stage. [25] 'The number of long stay schizophrenic hospital patients fell to zero'.[26] These results contrast sharply with results from a variety of locations where conventional medical treatment results show that over 50% to 80% of similar individuals 'treated' according to the medical model end up on long-term disability support,[27,28] with our local experience being that they join the 'revolving door' of repeated hospital admissions and a life unable to contribute to society, surrounded by family members whose ability to contribute to society is seriously hampered due to their caring role and frequently so compromised by their need to care that they also end up needing government support.

The long-term benefits of eliminating the likely need for lifetime medication and lifetime disability support and the added benefits of economic contribution of individuals and their loved ones to the community have led to OD being adopted in a wide variety of locations globally,[29,30,31] with the Australian New Zealand Journal of Family Therapy devoting an entire special edition to OD.[32]

We have suffered the ravages of 'two steps forward', now it is time to also take 'one step back' and provide optimum care for individuals facing mental health challenges. Talking therapy must have an equal place in recognition and government support for the management of individuals in distress as Medicare and PBS. The benefits of this are not only humane, but financial as well….. talking therapies have been shown to increase not only productivity, but their provision is far less costly than Australia's upward spiral of PBS, Medicare and hospital costs and the additional costs of managing the many untoward side effects of medications – including suicidality, violence and chronic health conditions.

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[17] Special Edition: (2015), The Biomedical Model of Psychological Problems: *Association for Behavioral and Cognitive Therapies*, (38) 7:169-243.
[18] Romme, M., Escher, S., (Eds), (2012), Psychosis as a Personal Crisis, an experience-based approach. Routledge
[19] Watkins, J., (2006), Healing Schizophrenia, using medication wisely, Michelle Anderson Publishing.
[20] Gosden, R., (2001) Punishing the Patient, Scribe Publications Melbourne
[21] Stasny, P., Lehmann P., (Eds) (2007), Alternatives Beyond Psychiatry, Peter Lehmann Publishing
[22] Read J., Mosher L.R., Bentall R.P., (2008) Models of Madness, Routledge
[23] Williams P., (2012) Rethinking Madness, Sky's Edge San Fransisco.
[24] Correll C.U., Galling B., et al (2018) Comparison of Early Intervention Services vs Treatment as Usual for Early-Phase Psychosis: A Systematic Review, Meta-analysis, and Meta-regression *JAMA Psychiatry* 75(6) 555-565
[25] Seikkula J., Aaltonen J., Alakare B., et al (2006) Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. *Psychotherapy Research.* 16(2):214-218
[26] Aaltonen J., Seikkula J., Lehtinen K., (2011) The Comprehensive Open-Dialogue-An approach in Western Lapland: 1. The incidence of non-affective psychosis and prodromal states *Psychosis* (3)3: 179-191
[27] Clemmensen, L., Lammers D., (2012) A systematic review of the long-term outcome of early onset schizophrenia *BMC Psychaitry 12:150*
[28] https://www.mentalhelp.net/articles/prognosis-and-recovery-factors-of-schizophrenia/
[29] https://www.theguardian.com/society/2015/oct/20/parachute-therapy-psychosis-new-york-uk
[30] http://power2u.org/alternatives-to-hospitalization/#PracticeGuidelines
[31] https://www.health.org.uk/improvement-projects/peer-supported-open-dialogue-pod-in-nhs-mental-health-services
[32] https://onlinelibrary.wiley.com/toc/14678438/36/1

Psychological services and talking therapy must be readily available as a fundamental component of routine care across all levels of our health care system, including psychiatric hospital wards, where, once an initial crisis had been overcome, the setting provides an opportunity to initiate a therapeutic relationship. In a new Model of Care, this relationship should continue into the community to assist in reducing the trauma currently associated with individuals returning to the community after discharge.

Continuity of care is essential for trust and success in management of mental illness.

Medication

Mentally unwell individuals cost society billions of dollars via very poorly designed mental health 'care' and support systems, causing vast billions to be spent on medication, much of which could be avoided had effective prevention, early intervention been available and had talking therapy been recognized as invaluable and integral to the management of mental illness.

The wasted dollars resulting from the cost of the medications themselves and resulting costs are discussed above.

DNA Testing

Psychoactive drugs, including legally prescribed medications can have adverse side effects including violence, homicide and suicide.[33] DNA testing to identify those at risk for these effects may save lives, and is especially warranted when individuals do not respond as expected to their medication.[34]

Polypharmacy

The frequent use of polypharmacy, which has been shown to be unnecessary and nto to increase therapeutic outcome in many cases, merely compounds the problems caused by the side effects of medications. The folly of prescribing additional medications without DNA testing the reason for unexpected lack of response to the first medication may lead to death.

Mental illness leads to loneliness, loss of social connection and chronic health conditions.

Loneliness is a public health challenge[35] with special needs to alleviate it within the mental health community. Social enterprises provide connection, purpose, fulfilment and training towards employment in the general community.

'Loneliness and social isolation can be as bad for patients as chronic health conditions. Loneliness puts people at a 50% increased risk of early death, compared to those with good social connections, and it is as bad for health outcomes as obesity'[36]

Strategies to attract, train, develop and retain a highly skilled mental health workforce, including peer support workers

Fix the system to attract caring, professional staff.

Dedicated staff are lost due to overwork in a dysfunctional system. Money helps, but caring staff need to see the benefits of their work and to work in a positive environment. Theirs is a stressful field. The

personal toll on dedicated staff needs to be minimized by adequate debriefing, availability of counselling to them also.

Clinicians at all levels need training in appropriate talking therapy, including areas such as Family Therapy, Open Dialogue, Peer Support, Trauma Informed Care.

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[33] https://www.madinamerica.com/2017/01/cyp-testing-prevent-dangerous-adverse-drug-reactions/

[34] Lucire, Y., Crotty, C., (2011)Antidepressant-induced akathisia-related homicides associated with diminishing mutations in metabolizing genes of the CYP450 family. *Pharmacogenomics and Personalized Medicine*,: p. 465-481

[35] VicHealth: https://www.vichealth.vic.gov.au/letter/articles/vh-letter-47-loneliness

[36] Royal College of General Practitioners, http://www.onmedica.com/getResource.aspx?resourceid=88f23ba5-74e9-46f3-8817-743662731031

Peer workers provide hope to consumers, in that they too will be able to function well. With good training, peer workers, by having lived experience, can be an invaluable asset to the mental health team. They can provide an understanding that comes only from lived experience.

To properly train workers in this field:

- Pharmaceutical organizations must be prevented from underwriting or funding in any way the training of clinicians, especially medically trained clinicians,
- Ghost writing of seemingly professionally written articles by representatives of pharmaceutical companies must be outlawed,
- Presenters at any lecture/symposium/workshop must clearly emphasize any affiliation with any pharmaceutical organization.

Delivery to all: Integrate services - Reduce fragmentation and compartmentalization of services

Strengthen pathways & interfaces between Victoria's mental health system and other services

'Mental illness' covers a wide heterogenous range of psychosocial disabilities, not only one 'illness'. Complexity is exacerbated because diagnosis is not physiologically measurable in concrete terms but is sign and/or symptom based, with many of the same combinations of symptoms appearing across a range of 'illnesses'. Thus quantitative hard scientific diagnosis of specific 'illness' is to some extent subjective and considered by some to be merely a 'classification' of symptoms rather than diagnosis of specific illness. Comorbidity with alcohol and other drugs is so common among the mentally ill that it has come to be named as 'Dual Diagnosis'.

Yet despite frequent comorbidity, some services choose to be so specialized that they exclude individuals suffering from challenges other than the one in which the service specializes – *e.g.* some psychiatric services exclude individuals with AOD issues, while some AOD specialists will not deal with the mentally ill.

Services offer help to individuals suffering from a range of symptoms, or operate in close collaboration among themselves so that no-one is excluded. Further discussion of co-morbidity is in Section xxx. DUAL DIAGNOSIS – MENTAL HEALTH ISSUES WITH ALCOHOL AND OTHER DRUGS

> L[redacted], a 24 years old lady suffers from severe mental health and intellectual disabilities. Due to her intellectual challenges, mental health facilities have refused to deliver appropriate services to her and vice-versa, leaving her and her family unable to cope. Her mother is burnt out by her needs and as a direct consequence, her mother, a highly regarded academic has been in a private hospital for over a month because she cannot cope with the situation.

Living with a mental illness and other co-occurring illnesses, disabilities, multiple diagnoses or dual disabilities; True Health Care includes care of general and physical Health

Mental health is a component of general health.

Lifestyle issues such as exercise, good nutrition, abstinence from tobacco, 'substances' and limited use of alcohol are core needs of good health. The mentally ill often have little social and emotional support and are therefore at great risk of poor habits. Additionally, the side-effects of their medication frequently enhances their vulnerability to unhealthy choices and poor health.

Individuals suffering mental health challenges die 10 to 25 years earlier than the general community.[37] This loss results from a combination of the high levels of multi-morbid systemic conditions including cardiovascular, respiratory, diabetes, infections and hypertension and suicide.[37] At any time, 80% of

[37] https://www.who.int/mental_health/management/info_sheet.pdf

individuals with mental health issues are suffering a serious medical condition[38.] with 60% of individuals with mental issues suffering from a chronic disease, 29.3% (n=1,172,000) suffering from one chronic condition and 30.5% (n=1,220,000) suffering from two or more.[39] As the mental health population dies 10-25 years younger than the general Australian population, these astounding rates of suffering for a young cohort indicate a significantly preventable Medicare and PBS burden on the community accompanied by further loss of economic potential of both consumers and carers.

It seems beyond belief that the general health of individuals treated within a health care system – sometimes an inpatient system – is ignored, In mental health, systemic side effects are routinely accepted without management until it is too late. By contrast, were this to occur in any other field of medicine, it would be regarded as professional negligence.

This situation is all the more disgraceful because much of this suffering could be prevented and money saved, by routinely including dietary and physical health personnel in mental health teams. The low cost of dietitian and exercise physiologist represents moral, ethical and financial investment that would pay off substantially in cost saving from Medicare and PBS and loss of economic participation by consumers and carers.

In our litigious age, it is worth considering what the legal position of services is in regard to informed consent in the context of excessive reliance on medication with serious, often life threatening side effects for conditions which have been shown to respond well to talking therapy. A class action in this context might end up being very costly to our mental health system.

In addition to social factors associated with mental health challenges, such as homelessness, poverty, poor nutrition, tobacco use, AOD and lack of social inclusion, many of the medications used in mental 'health' have side effects which are directly associated with chronic disease, including diabetes, obesity, cardiac and oral health. This is further reason for government to facilitate the use of evidence based talking therapies such as Open Dialogue which result not only in vastly better recovery rates, but also reduced need for medication and the consequences of the side effects of many drugs used in psychiatry.

ALL mental health facilities – inpatient and those within the community – need to include properly staffed exercise programmes, dieticians, regular care by general practitioners/ physicians and other allied health practitioners as part of routine care.

Across changes in location and acrossd all ages
To avoid increased stress leading to possible relapse, even if new services need to be introduced when individuals move location or grow older, there needs to be seamless passing of the baton, with gentle phasing out of earlier services. The current situation, sometimes with waiting periods to be accepted into new services while previous services are cut out is confusing, creates stress and can lead to relapse.

3. SUPPORT CARERS AND FAMILIES

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Carers, as their loved ones, are victims of a very poor dysfunctional mental health care system. It is because of this system that many are forced to give up their professional lives to becoming carers. In Australia in 2015, of 2.8 million carers, 240,000 care for individuals facing mental health challenges..[40] Conservatively, $1.2 billion is spent on supporting mental health carers, but it would cost $13.2 billion to replace them with formal support services.[40]

[38] https://www.equallywell.org.au/,

[39] https://www.vu.edu.au/sites/default/files/australias-mental-and-physical-health-tracker-background-paper.pdf,
https://www2.health.vic.gov.au/about/key-staff/chief-psychiatrist/chief-psychiatrist-guidelines/equally-well-in-victoria

[40] Diminic S., Hielscher E., et al (2016) The economic value of informal mental health caring in Australia:summary report. Brisbane: The University of Queensland

Accordingly the best help to carers would be:

- a well-run mental health system in which their loved ones recovered to enjoy contributory lives,
- the availability of safe, suitable accommodation for their loved ones and for themselves if needed,
- the availability of services to assist loved ones with daily living skills (if needed),
- the availability of services help loved ones find a purpose in life, including:
  - services providing activities, including physical activity,
  - services providing access to employment
- the fostering of social networks to avoid the loneliness[41] that plagues most mentally ill individuals,
- financial assistance to help in the caring role,
- financial compensation for loss of income due to caring.
- assistance in dealing with the NDIA.

The NDIS

ISFAF members consistently indicate serious shortcomings with all stages of the process. ISFAF members consistently complain that planners and other NDIS representatives have no understanding of mental health The following must be addressed urgently:

The application process

The application process is designed for articulate individuals with sound cognition, organization and communication skills. By definition, individuals with mental health disabilities lack these skills and are therefore significantly disadvantaged in their application. That NDIS staff frequently have no understanding of mental health, compounds this disadvantage.

Untrained / very poorly trained staff

Case Studies: Several carers have suffered medical complications such as high blood pressure as direct result of dealing with the complexities of the application process and NDIS staff with no understanding of psychosocial issues. N[redacted]'s daughter S[redacted], has suffered from schizophrenia for over four decades since her first menstrual cycle. She requires constant care with daily living skills. S[redacted]' illness is undoubtedly hormonal in origin and permanent. Yet N[redacted], a successful intelligent neurotypical professional was so shaken by the hostility she faced from NDIS representative ignorant of mental illness that she ran from the meeting in tears.

At an information seminar, the presenter, unable to answer my simple questions, admitted that she had been hired only a few days before! Her knowledge was scant, but on paper it seemed attendees were being serviced properly. Not only was precious time wasted for all, but the lady was being paid NDIS money to waste her and our time. What a waste of NDIS money intended to assist consumers to participate in community and to make economic contribution to community!

The ongoing process

In Victoria, many services to assist with daily living and social inclusion have closed. Closure has resulted in the loss of trained mental health workers who have been forced to find employment elsewhere. The situation is chaotic as some individuals who have managed to obtain approved plans are unable to fulfil them due to:

- delays in accessing their rightful funding,
- inability to find workers / services able to provide the needed help,
- if plans can be set into motion and an organization found to implement a plan for someone with mental health disability, service providers send a series of workers, some without mental health skills and therefore lack of continuity of care results in very poor care.

To learn that the money for professional services has been allotted but 'unspent billions' have effectively been stolen from the disabled[42] is horrifying for consumers and for carers who are yet again left in the position of needing to forego their own lives and their right to participate in, and contribute to, the Australian economy.

[41] Tackling loneliness: a public health challenge for mental health advocates?

Recent reports of various rorts, misuse and theft of NDIS money indicate that the system needs urgent improvement.

Inside and Outside the NDIS

It has been reported that about 90% of individuals with mental health disability will not qualify for the NDIS.[43] This is partly because of the episodic nature of mental disability. These unfortunate individuals have been left to their own devices because of the closure of the services upon which they relied. It can be expected that the mental and physical condition of consumers and their carers deteriorate as a consequence, that their economic contribution to Australian society is reduced and they become a greater burden on government assistance.

Case Studies: B[redacted], Q, A[redacted], Sh[redacted] and others. Prior to the roll-out, each of these individuals was occupied during the day in social activities that gave their lives meaning and overcame their loneliness. With the roll-out, most of these activities have closed down. They believe that in July several more, run by Mind, will also close, leaving them with NDIS money but lonelier than before and with little meaning in their lives. Their mothers fear increase in their AOD and gambling problems are inevitable and also fear return of suicidality

Via email to me from S[redacted] mother of B[redacted]:

'MIND Family and Carer Services are closing at the end of June when block funding ceases. Experienced staff, who supported carers and ran camps for consumers and carers, have been given notice. M[redacted] who had won awards for her service, has been given notice. Carers are at greatly increased risk of depression and the respite camps run by MIND Family and Carer Services provide the social support which protects against deteriorating mental well-being.

The Cheltenham Carers' Support Group organized by MIND will close. This support group has been a "lifesaver" for the participants.

The Soccer Group, which is usually followed by a barbeque, run by a MIND Community Mental Health Practitioner is closing. The Lawn Bowls group will cease. These activities for consumers of mental health services offered rare opportunities for consumers to participate in a community activity, increase their physical fitness and reduce their social isolation. The soccer was played indoors at Monash Caulfield Campus and participants came from as far away as Aspendale Gardens and Seaford.

There is a lack of community activities tailored to the needs of people experiencing serious mental health issues. Closure of these services will have a very negative effect on both consumers and carers. My son's NDIS Support Co-ordinator has struggled to find appropriate activities for my son. Other carers have experienced similar difficulties accessing suitable services. Carers have reported very positive effects of participation by their loved ones in the recreational group activities'

Via email from S[redacted]

'I can report that the services to assist with employment and to counteract social isolation for the mentally ill in the Peninsula area have all been incorporated into the NDIS. For people such as our son who will never apply for the NDIS this means a loss of services. ***There is no appropriate community assistance for such people.'***

Via email from K[redacted]

'Star Health's mental health management and group psychological programs funded under MHCSS are closed, including the critical Assertive Mental Health Outreach Team which provided assessment, engagement, linkage and support case management to people with mental illness experiencing homelessness.'

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[42] https://www.theaustralian.com.au/nation/politics/unspent-billions-shifted-from-the-books-of-ndis-agency/news-story/62fbd169e1f97b73d384439947d6e55, https://www.theaustralian.com.au/nation/politics/ndis-has-5bn-but-costs-to-soar/news-story/6026e5c16c82f8b42438

[43] Hancock, N., Bresnan, A., et al (2018). NDIS and Psychosocial disability – the Victorian Story: Insights and Policy Recommendations from Expert Stakeholders. *Report prepared for Psychiatric Disability Services of Victoria and SalvoConnect.*

https://probonoaustralia.com.au/news/2018/03/ndis-causing-growing-catastrophe-victorians-severe-mental-illness/?utm_source=Pro+Bono+Australia+-+email+updates&utm_campaign=72cf2f8458-EMAIL_CAMPAIGN_2017_08_18&utm_medium=email&utm_term=0_5ee68172fb-72cf2f8458-147645121&mc_cid=72cf2f8458&mc_eid=638c213cfb

4. DUAL DIAGNOSIS – MENTAL HEALTH ISSUES WITH ALCOHOL AND OTHER DRUGS

It has long been known that substance abuse and mental health issues frequently occur together and for successful management, integrated treatment is required.[44] Despite the acceptance of this co-morbidity and the common reference to it as 'Dual Diagnosis', in Victoria few services have a holistic approach, requiring referral to separate services, each with different waiting times, focusing on separate issues and possibly not 'talking with the same voice'.

Residential recovery units must be increased and they must offer continuity of care beyond their programmes.

Who would expect a serious addiction to be overcome in a programme of a couple of weeks without continued help?

Evidence based research on the best programmes needs to be sought and an increased number must be introduced into Victoria to deal with the the DOA epidemic.

In the meantime, experience shows that without follow-up relapse is likely and the money, effort, human energy and hope are lost.

Suicide can result from lost hope and the feeling of being in 'the recycle bin'

Case Study: N[redacted] an intelligent 32 year old suffers from schizophrenia and substance use disorder. He has used 'ice' from time to time. N[redacted] comes from a fully functional loving well educated family but has been unable to complete tertiary education. After some tempestuous years during which his parents were advised to force him out of their home due to N[redacted]'s drug habits, N[redacted] gained access and agreed to undertake a 12 week residential programme. Of the dozen or so others who commenced, N[redacted] was the only one to fully complete it. He returned to the family home, vowing that if he was forced out any time in the future, he would suicide. His mother rang me greatly distressed a few days ago. No-one has followed up to assist N[redacted]. He is clean of drugs, but remains in his room, totally amotivational and talking about suicide because he sees no positive future for himself. N[redacted] needs a mentor, activities, a future, help with education / employment, social connection. At 32 years, and now having fought many demons, remained 'clean', with the help of a proper system, he is well enough to be able to live a contributory life, instead of being thrown into the recycle bin by a non-functional system.

By contrast to the mental health sector, help for another child with severe autism has been wonderful, with mobile support team attending the home to help.

5. OTHER ISSUES: LIVING WITH MENTAL ILLNESS

Housing and Homelessness

Stable, safe affordable housing has widely been shown to be a first step in the recovery of homeless individuals with mental illness.[45,46,47.48] Not only is there a humane benefit but, by enabling recovery, 'housing first' facilitates productive economic contribution to community by those affected and saves government money by reducing the need for hospital and other support services.[49]

In 2016, almost 10,000 Victorians under 25 years old were either homeless or in unstable accommodation.[50] Among a sample of homeless individuals in Melbourne, 31% suffered mental health issues, with 16% **having developed mental health issues after becoming homeless**.[51] This data indicates that 1,600 young Melbourne individuals are at high risk of acquiring mental illness if they remain homeless. It can be reasonably assumed that state-wide the number will be a multiple of 1,600. The cost burden of this to our community, including the loss of productivity must be prevented by the provision of

[44] Lambert M., Conus P., et al (2005) The impact of substance use disorders on clinical outcome in 643 patients with first-episode psychosis. *Acta Psychiatr Scand* 112(2):141-8

[45] Pagett D., Gulcur L., Tsemberis S., (2006) 'Housing First services for people who are homeless with co-ocurring serious mental illness and substance abuse' *Research on Social Work 16(1):74-83*

[46] https://housingfirsteurope.eu/

[47] https://www.ahuri.edu.au/policy/ahuri-briefs/what-is-the-housing-first-model

[48] https://streetsmartaustralia.org/5-things-need-know-housing-first-homelessness/

[49] https://theconversation.com/study-shows-high-public-cost-of-homelessness-3059

[50] https://www.mhvic.org.au/images/PDF/Policy/FINAL__Saving_Lives_Money_Brochure_HR.pdf

[51] https://www.sbs.com.au/topics/life/health/article/2017/06/27/surprising-link-between-mental-illness-and-homelessness

stable, affordable housing. Adult unemployment rate rises to 90% among individuals who were homeless before 15 years of age,[52] further demonstrating the long-term loss that results from homelessness.
In summary, society gains many times over from every cent spent on providing safe, supported housing for individuals who are homeless. Without safe, congenial, affordable accommodation, individuals cannot be expected to feel hope and self-worth and consequently mental health care cannot succeed.

Loneliness, Employment, Quality of Life Issues: Support Services within the Community

The spectrum of mental health issues is wide. 'One size' does not 'fit all'. This holds true for accommodation and many other quality of life issues. Without adequate supports within the community, hope and purpose are lost, mental health deteriorates and suicide looms.

Community services assisting with daily living, providing activities and purpose to life have never been sufficient, but with the introduction of the NDIS, the vast majority of local services which assisted with daily needs have disappeared. This may apply especially to Victoria, where it was reported that under Mary Woolridge, money for these services was diverted into the NDIS. However delays in accessing the NDIS and that over 90% of individuals with mental health disability will not qualify for the NDIS[43] have left many individuals without the services they relied on. The resultant loss of dignity and purpose for consumers and the resultant burden on carers, is immoral, heartless and cruel. Furthermore it results in carers being unable to pursue their own lives, deterioration in their own mental health[53], reduction in their ability to contribute to the Australian economy and is often a path to poverty.

The increase in Headspace funding promised via the 2019 Budget promises some hope for youth, but it is not enough. Adults also need community based organizations, preferably Healing Centres to which they can turn to 24/7.

In Conclusion

On behalf of members of Inner South Family and Friends, I thank the Victorian Government and the Commissioners for the opportunity to present our vision for a functional mental health system which parallels the quality of general health care in Victoria and includes comprehensive health and physical care.

Comprehensive health care can only be obtained within the community, hence the provision of access by all to extensive community based mental (and general) health care is an integral part of government responsibility. General health care must blend with specialized mental health services to avoid early death and the chronic disease which currently plague the mentally ill.

All individuals need to have hope and to feel that their life has purpose. Without this, the path is to depression and suicide. Mental health care needs to provide a means whereby individuals whose psychosocial disability has isolated them from the community are able to find purpose and meaning.
The escalating cost of pharmaceutical management and polypharmacy is huge both directly and indirectly via the toll and costs of the side-effects of the medications. This can be reduced using alternate treatment methods that have been shown to be as effective and, in some cases such as Open Dialogue, to be more effective than medication.

Individuals cannot achieve mental well-being in an unsafe environment and without a roof over their heads. Suitable affordable housing, supported if so needed, is an essential component to mental health care.
We are in the midst of a drug epidemic wrecking the lives of both users and those around them and leading to death of both groups. This epidemic is prevalent among youth and is therefore this tragedy must be averted to prevent it escalating into future generations. Prevention from early school level, education of all who may be useful in helping to avert the crisis, early intervention, increased rehabilitation opportunities, improved social circumstances are some of the many strategies required, but all must be pursued if Victorians are to live safely.

[52] Saving Lives, Saving Money (2018) Mental Health Victoria.
https://www.mhvic.org.au/images/PDF/Policy/FINAL__Saving_Lives_Money_Brochure_HR.pdf
[53] see Case Study herein: 'Delivery to All'. L[redacted].pp xxx