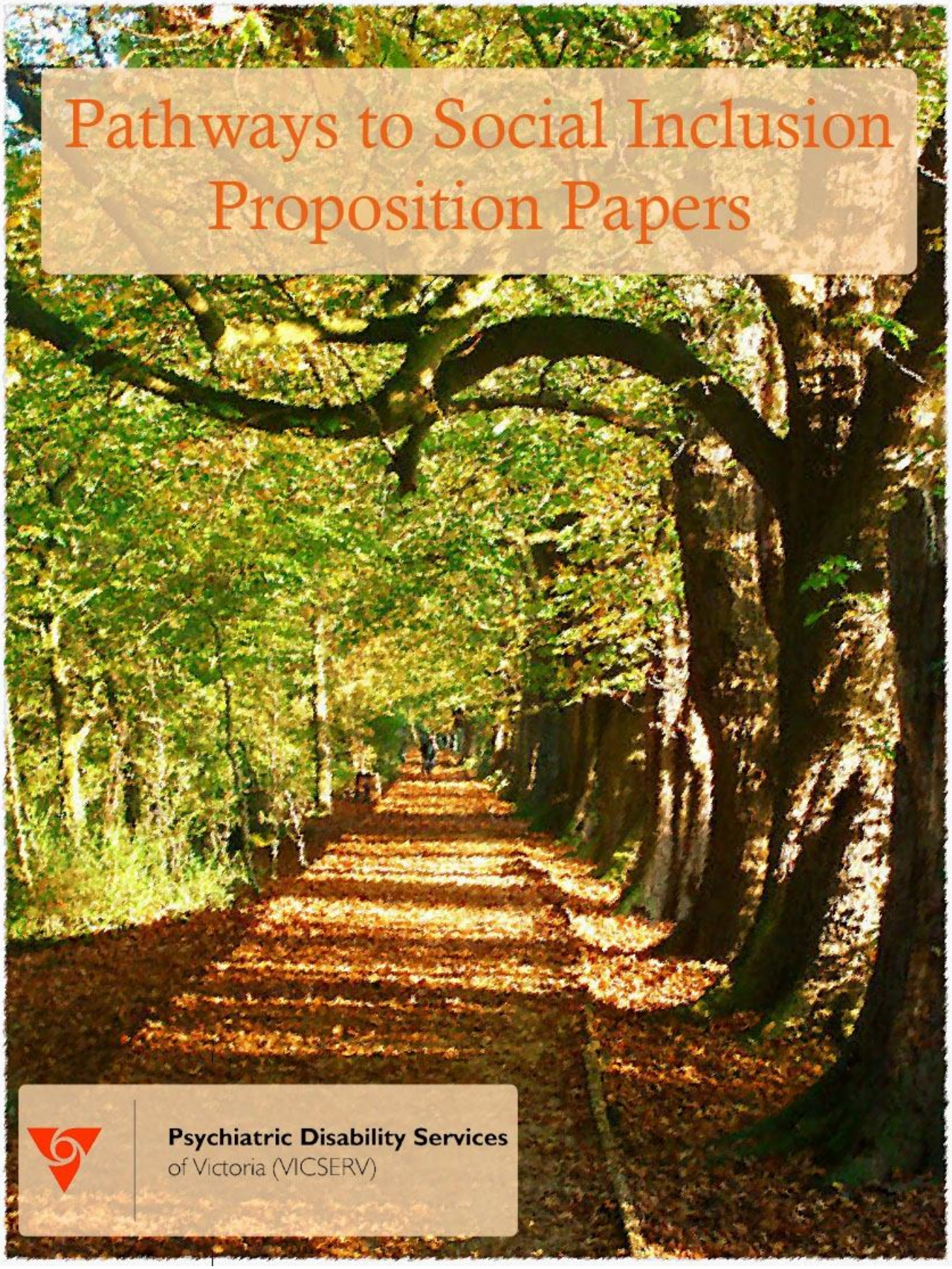
Pathways to Social Inclusion Proposition Papers



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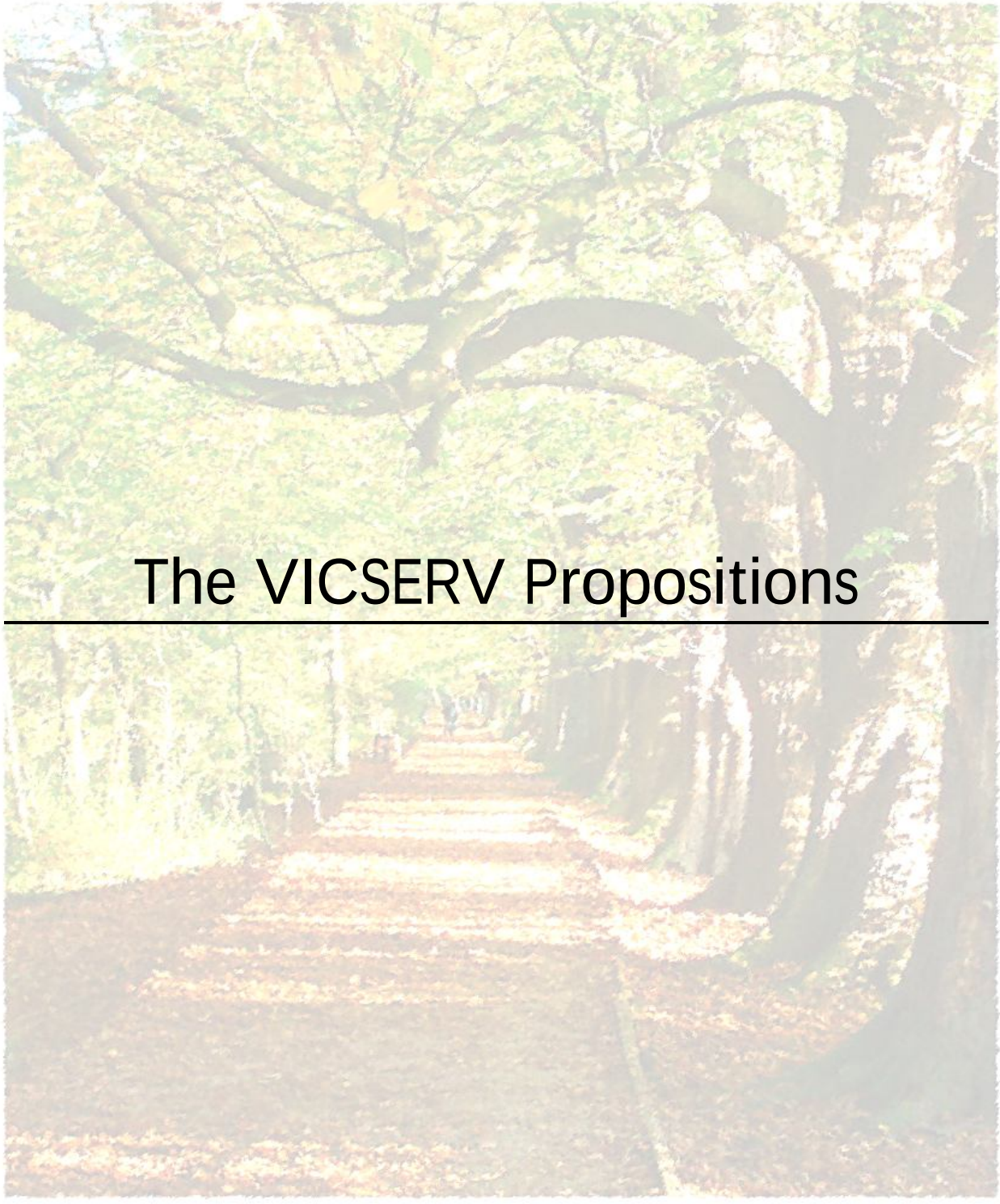

The VICSERV Propositions

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About VICSERV

'... a world of opportunity for people with a psychiatric disability' is our vision.

Psychiatric Disability Services of Victoria (VICSERV) Inc. is the peak body for Psychiatric Disability Rehabilitation and Support Services in Victoria, Australia.

Our member agencies provide housing support, home-based outreach, psychosocial and pre-vocational day programs, residential rehabilitation, mutual support and self help, employment, training and support, carer education, respite and advocacy.

What are the *Pathways to Social Inclusion*?

A commitment to human rights and good practice evidence combine to underscore the importance of adopting social inclusion as a driver for mental health reform and a shared framework for measuring and monitoring outcomes.

Better outcomes for people living with serious mental illness will not be achieved simply by doing 'more of the same'. VICSERV intends to work with a range of stakeholders to ensure that the mental health reform agenda recognises this fact. Our systems must be redesigned around the person, not the illness; the community, not the institutions or providers.

The current emphasis on clinical intervention in the absence of adequate social infrastructure and supports in relation to health, housing, employment, education, and community strengthening has not achieved the outcomes intended by de-institutionalisation. It is time to take a more balanced approach – one that makes economic sense and offers dignified solutions to consumers, carers, families and communities.

In order to demonstrate the value of this approach, contribute to and promote useful debate, VICSERV has developed four propositional papers, together constituting the *Pathways to Social Inclusion*. The papers are:

Social Inclusion: an outcome measure for the mental health service system – the first in the series and a conceptual introduction to the others

Health Inequalities: policy and practice failure

Housing and Support: a platform for recovery

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Economic Participation: employment and education – changing outcomes

The VICSERV focus and target groups

The focus of the four propositional papers is on:

- People living with low-prevalence mental disorders. This includes younger people and others with recent onset, those experiencing single episode illness, and those with longer-term experiences of illness.

- Carers and families of people with severe mental illness.

- Communities in which people with severe mental illness live and seek to participate.

- The full range of services that provide treatment and supports.

Design of the papers

Each paper is written in two parts. The first part summarises the relevant evidence for change including current outcomes, systemic weakness and barriers, and good practice knowledge. These summaries also detail the VICSERV propositions for action, research, linkage and investment. The second part of each paper provides a more in depth analysis of the issues and is extensively referenced to relevant literature.

Whilst each paper has been written as a 'standalone' document, the set of documents when read together builds the most compelling case for change. Care has been taken to limit repetition across the papers; however, there is some cross-referencing to allow for each paper to be used independently.

Whilst the *Pathways to Social Inclusion* considers and responds to issues currently being raised and discussed in broader forums at both Commonwealth and State levels—including Victoria's *Because Mental Health Matters* Consultation Paper—it has not been prepared as a specific policy response.

The *Pathways to Social Inclusion* intends to contribute and add value to a range of policy debates within the mental health sector and in other critically linked areas including community strengthening, health, housing, employment and education.

An incomplete process

VICSERV is aware that the work is incomplete:

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- The propositions offered do not represent all the viable and valuable options for changes – but they do reflect important opportunities and urgent need.

- Evidence and information is continuously emerging and must be incorporated into thinking and discussion.

- The papers reflect a selected and prioritised focus. However, there are a number of other critical issues that directly relate to mental health outcomes and a social inclusion agenda.

- Additional themes that VICSERV is committed to exploring over time include diversity, carers, and mental illness and the criminal justice system.

An invitation

In developing and promoting these propositional papers, VICSERV is not simply responding to debate. We are inviting the diversity of stakeholders, who have a role in making a difference to mental health outcomes for people living with a severe mental illness, to engage with our sector in joint work to create new solutions. We are concerned to see the development of broadly integrated and aligned ways of working that will achieve inclusive communities and support people living with a mental illness to reach their full potential.

Papers can be accessed after February at www.vicserv.org.au or telephone (03) 9519 7000.

VICSERV Board: August 2008

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Highlights

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VICSERV Pathways to Social Inclusion

Social Inclusion: an outcome measure for the mental health service system

Facing the facts

- 85.2% of people living with severe mental illness are recipients of a government pension
- Their death rate is 2.5 times greater than that of the general population
- The unemployment figure for this group is 19.5%
- Carers, on average, contribute over 100 hours per week caring for those with mental illness.

Better outcomes are possible

- Evidence shows that social inclusion is intrinsically linked to recovery
- Paid work is associated with reduced psychiatric symptoms and higher functioning
- Increased participation in meaningful vocational activities by just 10.0% of unemployed people with psychosis could potentially save society around $147 million per annum
- It is time for a new agenda that fundamentally shifts and shares effort to building socially inclusive communities.

Our call for action

- Invest substantially in the PDRSS sector
- Use and add to the evidence of good practice
- Create effective links at policy, planning and implementation levels
- Develop a benchmarking framework that provides for comparison of agreed outcome measures relating to health, housing, employment and education.

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VICSERV Pathways to Social Inclusion

Health Inequalities: policy and practice failure

Facing the facts

- People with mental illness have a higher death rate across each of the main physical causes
- Their death rate is 2.5 times greater than that of the general population
- People with mental illness are 30% more likely to die from a cancer diagnosis
- The death rate from heart disease has increased substantially for women with mental illness.

Better outcomes are possible

- Opportunities include tailored prevention and early intervention strategies
- Building linkages between mental health and primary and sub-acute/acute care
- Formally highlight the need for knowledge to be built in order to provide the appropriate supports and develop a carer health agenda
- The specific experiences and needs of people living with severe mental illness must be considered if we are to support their engagement with health interventions and address their profound health inequalities.

Our call for action

- VICSERV proposes the immediate establishment and funding of a prioritised (ill-) health and mental illness research agenda
- Sector self-review of all PDRSS program types for 'whole of person health approaches'
- 'Beyond Mental Illness' training program for clinical mental health professionals and GPs
- Targeted health promotion and secondary/tertiary prevention strategies.

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VICSERV Pathways to Social Inclusion

Economic Participation: employment and education – changing outcomes

Facing the facts

- Workforce non-participation amongst people with psychotic disorders is more than 72%
- People with psychiatric disabilities have the highest rate of workforce non-participation compared to other disabilities
- They represent the largest disability group accessing disability employment services (at 30.0%) despite faring worst in employment outcomes
- Unemployment has been found to contribute significantly to the total cost impact of psychosis on the community.

Better outcomes are possible

- Employment has been found to diminish symptoms, reduce hospitalisations and increase independence
- Personal contact with those experiencing mental illness can counter myths and stigma
- Increased participation in meaningful activities by just 10% of unemployed people with psychosis could potentially save around $147 million per annum
- The goal of realising a vocation in life is a high priority for many people living with severe mental illness.

Our call for action

- A long-term, effectively aligned approach achieved through targeted policy
- Increase the peer workforce (people living with mental illness) in the PDRSS sector
- Better links to employment services, mental health clinical services, PDRSS programs and employment services
- Extend the evidence base for practice.

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VICSERV Pathways to Social Inclusion

Housing and Support: a platform for recovery

Facing the facts

- At least 42% of people with severe mental illness are currently housed in tenuous forms of accommodation
- Research shows that two-thirds of consumers identify housing and housing support as the most important issues in their lives
- Only 27% of people with psychiatric disability are buying their own homes compared to 70% of the mainstream population
- Housing supply is insufficient. Private rental is becoming increasingly out of reach.

Better outcomes are possible

- Housing means affordable and appropriate accommodation plus the supports necessary to maintain tenure
- There is a strong association between housing and clinical improvement
- The needs of people living with severe mental illness seeking stable and appropriate 'homes' must be addressed if we are serious about supporting recovery
- We know there are cost savings to be made in a range of areas including clinical, emergency and crisis services through the provision of stable, appropriate housing.

Our call for action

- Introduce housing policy and options with an explicit focus on people recovering from severe mental illness
- Scalable, flexible models of housing-linked support
- Economic modelling of costs/benefits of stable housing
- Address the critical issue of ageing carers and housing risks.

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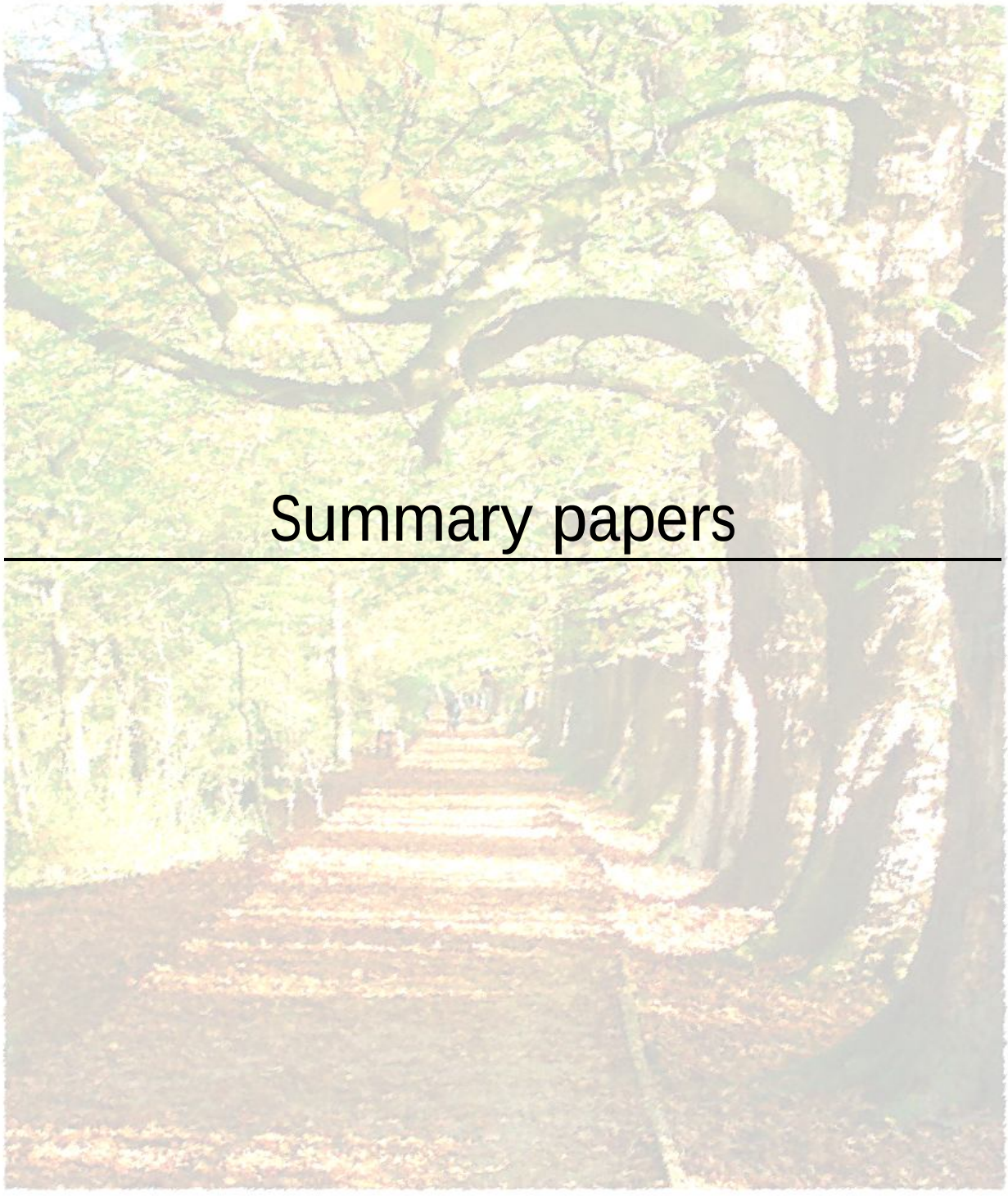

Summary papers

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Social Inclusion: an outcome measure for the mental health service system - *Summary paper*

Twenty-five years on… the unfinished business of de-institutionalisation

During the 25 years since de-institutionalisation there have been three national mental health plans and a national inquiry into the human rights of people with mental illness. Despite this effort and the intention that drove de-institutionalisation, the health and life outcomes for people living with serious mental illness are, overall, very poor. People living with severe mental illness are homeless (and imprisoned) more often than others, their health status is poor, they are more likely to be unemployed, and their engagement with education and connections to the community are often tenuous.

- The unemployment figure for this group is 19.5% (compared to 4.2% for the overall population.)

- 47.8% have not finished secondary school or achieved post-secondary qualifications and 85.2% are recipients of a government pension.

- 42.0% live in unstable forms of housing (i.e. institutional settings, hostels, boarding houses, rented rooms, crisis accommodation, shelters) or are amongst the primary homeless.

- Their overall health status is far lower that the mainstream population resulting in significant health inequalities. The death rate of people with mental illness is 2.5 times greater than that of the general population, which is equivalent to a life expectancy of 50 to 59. People with schizophrenia have a mortality rate that is up to three times higher than that of the general population.

- The 12-month prevalence rate of psychosis in the prison population is 9.0%, which is 30 times higher than the non-prison population.

- There is ongoing stigma and discrimination against people with severe mental illness.

- Carers, on average, contribute in excess of 100 hours per week caring for those with mental illness. They too, are at risk of poor health outcomes.

Clearly, current policy and service responses are inadequate for people with severe mental illness, their carers and families. Individuals, service systems (including mental health) and communities are yet to respond to de-institutionalisation in ways that truly work to support recovery and the fulfilment of core human rights. The solution will not be found in 'more of the same'. It is time for a new agenda that fundamentally shifts and shares effort to building socially inclusive communities in which people living with serious mental illness are effectively supported to engage and participate in society.

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A growing commitment to social inclusion

In July 2008, Australia became one of the first nations to ratify the *United Nations Convention on the Rights of Persons with Disabilities*. Signatories to the Convention agree to promote communities in which all people with disabilities are included as equal and active citizens. There is currently also considerable interest in the notion of social inclusion across government jurisdictions – in particular, the creation of a new Social Inclusion Board and Minister for Social Inclusion at the federal level.

In order to complete the tasks associated with de-institutionalisation and achieve better outcomes for people living with severe mental illness, mental health reform (approaches and systems) must be clearly linked to achieve authentic social inclusion. It is critical that the mental health change agenda does not take a narrow, 'siloed' approach that over-emphasises clinical responses and fails to tackle seriously the broader socio-economic determinants and risk factors that contribute to relapse, which prevent recovery.

Because Mental Health Matters

In Victoria, there is a review and reform process underway for the mental health service system. This ministerially initiated process includes the release of a consultation paper, *Because Mental Health Matters*. The paper identifies several issues associated with the operation/impact of the current system, including the lack of respect, dignity, involvement and control given to consumers in some parts of the sector. The paper also acknowledges a growing concern for the poor treatment of people with mental illness in other spheres of life including housing, employment, education, and day-to-day aspects of community and neighbourhood living.

Whilst the paper recognises the importance of providing psychosocial supports to improve daily living skills and address health and welfare issues that can impact on continued recovery (e.g. housing needs and connection to family and community), there remains a serious risk that the new policy direction will simply see 'more of the same':

- Continued dominance of the clinical/medical model in terms of authority, investment and focus of reform.

- Continued neglect of the physical wellbeing of people living with a severe mental illness.

- Failure to take the necessary steps to broaden the agenda and ensure improved mental health outcomes through social inclusion strategies – including (but not limited to) community development and capacity building efforts to address the causes and 'symptoms' of stigma.

- Limited recognition and understanding of the role of carers as partners in the service system and their needs during the course of their life stages.

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- Limited responses to cultural diversity i.e. modification of dominant paradigms rather than deep reform that works in harmony with cultural understandings of illness and health.

- Limited concepts of integration i.e. substantial focus on the relationship between clinical mental health services and Psychiatric Disability Rehabilitation and Support Services (PDRSS).

- Failure to achieve the level of upfront investment and associated reform required to provide housing, employment, education and other supports known to make a positive difference to recovery and overall outcomes.

Mental health reform in Victoria (and elsewhere) must be clearly underpinned by a social inclusion agenda that leads and links across other departments/sectors including health, housing, education, employment and community strengthening. This social inclusion response must be fully integrated into clinical and support services. The whole person (not the mental illness) and whole communities must be at the centre of this response.

Social inclusion, recovery and the business base

A social inclusion approach to mental illness makes good policy sense. Social inclusion is intrinsically linked to recovery, often described as a 'journey' towards greater participation and citizenship. Evidence shows:

- A sense of belonging to community makes people feel cared for, loved and valued, which in turn protects wellbeing. On the flipside, exclusion is linked to unhappiness, illness and reduced life expectancy. There is a strong correlation between poor social networks and mortality from almost every cause of death.

- There is better recovery after disease when opportunities for social interactions are in place.

- Social inclusion is linked with relapse prevention for people with severe mental illness.

- Low social supports increase the risk of onset and decrease the chance of recovery.

- Paid work is associated with reduced psychiatric symptoms, higher functioning, improved sense of self worth, and significant improvement in social skills.

Currently, the cost of treatment is extremely high, with bed-based hospital care the main driver/contributor. This investment is not achieving desired outcomes. Evidence indicates that considerable cost benefits are to be attached to increase community-based supports that address 'whole of life' needs. For example:

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- Increased participation in meaningful vocational activities by just 10.0% of unemployed people with psychosis, could potentially save society around $147 million per annum in costs. If the rate of participation increased by 30.0%, the savings would be in the order of $441 million per annum.

- The estimated average recurrent cost of providing one mental health hospital bed is around $150,000 per year compared to one unit of public housing at $5,990 per year.

A balanced approach: a broader focus for mental health services in Victoria

Whilst respecting the importance of clinical treatment to stabilise symptoms, it is time to redress the imbalance that sees disproportionate investment in this aspect of acute and continuing care. It is time to develop a mental health policy/system that demonstrates an understanding of a 'whole of person', 'whole of life', consumer and community-centred response and its role in improved outcomes—and how this response can optimise continued investment in clinical services as well.

It is time to create an integrated and forward-thinking response that will:

- Address, in equal measure, the social and clinical risk (and protective) factors that impact on people living with severe mental illness.

- Formulate specific policy and strategy in the areas of primary health (and chronic illness), housing, education, employment and community strengthening that respond to the needs of people with severe mental illness.

- Invest substantially in the PDRSS sector and the development of flexible services/funding models that allow for:

    - Scalable responses
    - Linkage with clinical mental health services and other sectors (e.g. health, housing, employment and education)
    - Targeted, non-emergency after-hours support
    - Consistent and adequately-resourced approaches for working with carers and families.

- Reliably forecast need to enable considered, proactive and integrated responses.

- Use and add to the evidence of good practice (including working with diverse communities).

- Invest in addressing stigma and changing attitudes.

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- Assure adequate long-term investment in stable and appropriate housing options.

- Create effective links at policy, planning and implementation levels. Better linkage and synergy must be achieved across government jurisdictions (federal and state) as well as with an extended range of policy makers and funding bodies, who have the capacity to be part of the solution.

The VICSERV propositions: social inclusion, innovation and better outcomes

A commitment to human rights and good practice evidence combine to underscore the importance of social inclusion as a driver for mental health reform and a shared framework for measuring and monitoring outcomes.

Overarching VICSERV approach

In order to emphasise the need for this approach VICSERV has developed four propositional papers. The current paper, *Social Inclusion: an outcome measure for the mental health service system,* is the first in the series, serving as a conceptual introduction to the others:

- *Health Inequalities: policy and practice failure*
- *Housing and Support: a platform for recovery*
- *Economic Participation: employment and education – changing outcomes*

Each paper summarises the relevant evidence for change including current outcomes, systemic weakness and barriers, and good practice evidence. Importantly, each paper proposes a set of action, linkage and investment priorities. Together, the papers constitute the ***VICSERV Pathways to Social Inclusion*.** They are intended to add to the discussion on their respective issues and provide shared and concrete ways forward.

Papers can be accessed at www.vicserv.org.au or telephone (03) 9519 7000.

Additional proposition – benchmarking

Whist the propositions contained in the papers build towards achieving markedly improved levels of social inclusion—and as a consequence, better mental health outcomes—it is also necessary to develop change goals and benchmark achievement to fully embed social inclusion as a jointly-owned outcome.

VICSERV proposes the development of a benchmarking framework that provides for comparison of agreed outcome measures (at agreed intervals in time) related to health, housing, employment and education:

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- between Australia and other OECD countries,

- between Victoria and other states and territories within Australia,

- with current outcomes in the relevant sectors, and

- with current ways of working in clinical and PDRSS sectors.

Investment required

There is an initial piece of work to be undertaken to determine a set of (broad and higher level) measures and engage key stakeholders. It is proposed that this work be initiated through the new Social Inclusion Board and is supported by mental health reform leaders in Victoria and representatives from other (state and national) bodies. The level of investment requires further consideration, although it is expected the cost will not be particularly high.

In a parallel process, VICSERV, through its members, intends to develop its own 'scorecard' approach in relation to ways of working and outcomes that reflect a social inclusion agenda.

Looking forward

The *VICSERV Pathways to Social Inclusion* is a dynamic and ongoing piece of work that VICSERV intends to update and add to over time. Upcoming priority areas for investigation and a propositional approach include:

(a) *Diversity – different needs, different approaches, different outcomes.* This work will consider in depth, outcomes, barriers and approaches using gender, indigeneity, cultural diversity, and sexual orientation as lenses for analysis.

(b) *Carers and Families – hidden partners.* This work will consider in depth, the contributions and roles of carers, the different cohorts of carers, and the needs of carers at stages of their lives and in the recovery journey of care recipients.

(c) *Justice, Injustice and People Living with Mental Illness.* This work will consider the experiences and needs of people living with a severe mental illness in the criminal justice system, as well as systemic requirements necessary to enable improved responses to illness symptomatology and support needs.

VICSERV is interested in and willing to undertake developmental work in partnership with governments and/or key sector stakeholders to progress these ways forward.

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Health Inequalities: policy and practice failure
Summary paper

The disturbing facts[1]

- People living with severe mental illness have an overall health status that is far lower than that of the mainstream population, resulting in significant health inequalities.

- The death rate of people with mental illness is 2.5 times greater than that of the general population, which is equivalent to a life expectancy of 50 - 59. People with schizophrenia have a mortality rate that is up to three times higher than that of the general population.

- People with mental illness have a higher death rate across each of the main physical causes, with heart disease causing the highest number of 'excess' deaths. The death rate from heart disease has not declined for this group in recent years, in stark contrast to the general population and has actually increased substantially for women with mental illness.

- The number of deaths in people with mental illness, due to main physical causes, far exceeds the number of hospital admissions for related conditions. Conditions such as heart disease are not being picked up or treated until it is too late. Whilst the incidence of cancer appears to be no different for people with a mental illness and the general population, people with mental illness are 30.0% more likely to die from a cancer diagnosis.

- Coexisting physical conditions found in patients with severe mental illness include diabetes, hyperlipidaemia, cardiovascular and respiratory disorders, obesity, malignant neoplasms, HIV/AIDS, Hepatitis C, hyperprolactinaemia, osteoporosis, irritable bowel syndrome, Parkinson's disease, accidental poisonings (related to prescribed and illicit substance use), injuries inflicted on the person, and poor nutrition.

- An estimated 20-50% of new clients of adult mental health services in Victoria present with a coexisting substance abuse problem; and the prevalence rate is even higher for young adults.

- People living with severe mental illness have poor oral health. Experience indicates these people require 23.0% more dental treatment services and have 36% more extractions than other low-income consumers.

- People living with severe mental illness often experience high rates of co-morbidities due to high-risk health behaviours interacting with mental illness and vice versa. These behaviours include cigarette smoking, alcohol and other drug abuse, obesity, poor diet, and lack of exercise.

[1] Please refer to *Health Inequalities – Policy and Practice Failure. Background Paper* for details and references.

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Is it them or is it us?

People living with severe mental illness literally suffer the consequences of policy and system failure to address social determinants of health (housing, employment, income, education, social inclusion, etc.) and to ensure access to health services that are able to effectively address their needs.

Practitioner responses to people living with severe mental health illness often fail to demonstrate an awareness of the connections between physical health conditions and their contributing factors.

We have created a disjointed service system where there is:

- Poor inter-sectoral collaboration, knowledge transfer and resource sharing between the mental health service sector and primary care and (non-psychiatric) acute care sectors.

- A tendency (likelihood) for specialist mental health, clinical and PDRSS workers to overlook and/or under-address the physical health issues of their patients/clients.

- Reluctance on the part of other health providers to engage and treat clients whose behaviours are affected by mental illness.

People living with severe mental illness 'fall between the cracks' of service systems leaving a range of physical conditions ignored and untreated, resulting in tragic health outcomes.

The health costs of caring

Carers can spend over 100 hours a week 'on the job'.[2] The experience can, for at least some periods, be fraught with difficulty and stress. As with many aspects of the carer role, necessary questions have neither been asked nor answered. Given both the rights and role of carers, it is time to consider their health and wellbeing as part of a comprehensive response to the impact of mental illness.

VICSERV is not yet making specific propositions in this area but considers it important to formally highlight the need for knowledge to be built in order to provide the appropriate supports and develop a carer health agenda. VICSERV plans to explore with carers (and key carer organisations) questions related to their health experiences and needs in the next phase of proposition development. VICSERV invites interested stakeholders to engage in dialogue and a partnership approach to this work.

[2] See *Social Inclusion – An Outcome Measure for the Mental Health Service System. Notes on Context, Definition and Evidence* for details.

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Addressing health inequalities: moving forward together

The specific experiences and needs of people living with severe mental illness must be considered if we are to support their engagement with health interventions and address their profound health inequalities.

Opportunities include:

- Integrated, multi-disciplinary approaches – new models and ways of thinking, funding and working.
- Tailored prevention and early intervention strategies.
- Building linkages between mental health and primary and sub-acute/acute care.
- Making improvements in referrals (with an emphasis on supported referral) and other aspects of service coordination.

Capturing these opportunities requires:

- Authentic engagement of consumers and carers in setting their own health agenda.
- Building the evidence for practice.
- Utilising the PDRSS sector as a platform for engagement and linkage.
- Innovation supported by policy and investment.
- Partnerships.

The VICSERV propositions: A multi-faceted strategy

The evidence indicates an urgent need for a comprehensive response to address the substantial health inequalities experienced by people living with severe mental illness. To this end VICSERV proposes a multi-faceted action strategy comprising four strategy elements. These are:

- Research.
- Practice Innovation.

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- Workforce Awareness and Development.

- Targeted Policy and Investment.

1. Research

A key to making long-term difference is knowledge and using that knowledge to raise awareness and change policy and practice. There is a need for a comprehensive (ill-) health and mental illness research agenda that includes:

- Exploration of the relationship between physical wellbeing (illness) and recovery (social inclusion).

- Health status analysis with a focus on age, gender, length of time living with a mental illness, and other factors. This may include studies that quantify the costs of physical ill health borne by individuals with severe mental illness and society (including government).

- Better understanding of health promotion models appropriate for people living with severe mental illness.

VICSERV proposes the immediate establishment and funding of a prioritised (ill-) health and mental illness research agenda in Victoria that is built on active collaboration between key stakeholders including:

- Government as co-leader, (part) funding body and partnership broker.

- Consumer representation.

- VICSERV as sector agent and co-leader.

- Research expertise; health promotion expertise.

- Representation from clinical mental health, primary and acute health sectors.

Investment required: $150,000 in the first year for establishment of the prioritised research agenda and seed funding for at least one of the agreed research priorities. It is expected that a realistic three-year funding proposal (including funding models) would be developed in Year One.

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2. Practice Innovation

(a) Pilot integrated PDRSS and primary health responses. This practice innovation involves the Department of Human Services (DHS) funding six pilot sites—across inner city, outer suburban, regional and rural Victoria—to integrate primary health and PDRSS service responses. It is proposed that the pilots are funded to operate for a three-year period initially. Pilots would reflect different models in order to enrich sector learning, although it is expected that all would:

- Include multi-disciplinary teams.

- Be informed by the experience of primary health services developed for injecting drug users, RDNS Homeless Persons services and other relevant practice models.

- Integrate, in some way, the concept of health self-management and health coaching (including peer coaches) using adaptations of the Flinders, Wagner or other evidence-based models.

It is proposed that funding be a joint initiative of the Government Mental Health and Primary Care Branches and that funding allows for a substantial evaluation. VICSERV would expect to make a significant contribution to informing the design of the pilot.

Investment required: $300,000 per pilot site per annum for three years ($5.4 million) plus $150,000 for pilot evaluation.

(b) Targeted health promotion and secondary/tertiary prevention strategies. Fund at least one sector-wide health promotion initiative that includes secondary and tertiary prevention strategies—specifically designed to target consumers living with severe mental illness and address risk factors related to one or more of the chronic illnesses demonstrably impacting on the population e.g. cardiovascular diseases or diabetes.

It is proposed that the overarching strategy be developed collaboratively between DHS, VICSERV, consumer representatives and key health promotion bodies. It is anticipated that implementation would occur through partnership approaches involving PDRSS, clinical mental health services, primary health and health promotion agencies and, potentially, Mental Health Alliances and Primary Care Partnerships.

Evaluation of this practice innovation could be usefully linked to the proposed research agenda.

Investment required: $100,000 in the first year for the design of the strategy and to support engagement in and coordination of implementation partnerships. It is expected

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that implementation costs, funding options and requirements would be developed in Year one as part of the design process.

(c) Sector self-review of all PDRSS program types for 'whole of person health approaches'. VICSERV will lead the sector in a process of internal review of all PDRSS program types to identity opportunities for integrating 'whole of person health approaches', good practice models, and practice gaps. This initiative will form part of VICSERV's quality improvement agenda and is intended to be implemented over a two-year timeframe.

Investment required: the cost of this initiative would be fully absorbed into VICSERV's operating costs.

3. Workforce Awareness and Development

(a) Health awareness training program for the PDRSS workforce. The VICSERV Training Unit will develop a Health Awareness Training Program that includes training for new, longer-term staff and management across the PDRSS sector on:

- Health issues for consumers i.e. prevalence, risk and protective factors, gender analysis.
- Health risks, side effects, medication (psycho-pharmaceuticals) and informed choice.
- Working with consumers to identify and manage health issues and navigate/access the health system.
- Designing PDRSS program activities that support physical wellbeing.

It is anticipated that training modules will be readily adapted for use in other sectors and VICSERV would aim to make the product available though Mental Health Alliances.

Investment required: DHS is requested to provide once-off funding of $40,000 to assist VICSERV in designing the program and developing quality resources (hard copy and online). Implementation of the training across the PDRSS sector will be resourced through VICSERV's training budget.

(b) Beyond Mental Illness Training Program for clinical mental health professionals and GPs. This training initiative will assist in bringing about the attitudinal change across the necessary sectors to make a difference to the health outcomes of people living with severe mental illness. The training is intended for clinical mental health professionals and GPs—those positioned to make a substantial difference to consumers in identification and follow up of physical vulnerabilities and illness.

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It is proposed that the work undertaken by VICSERV in developing training for the PDRSS workforce (see above) will inform this initiative. It will, however, be necessary to assure broader engagement and ownership, and it is proposed that DHS take an active 'sponsorship role' in establishing the right platforms and partnerships for the Beyond Mental Illness Training Program.

Investment required: To be determined.

4. Targeted Policy and Investment

Immediate and specific policy responses are required to address the profound health inequalities experienced by people living with severe mental illness. Policy must include targets to reduce the burden of disease carried by this population group, address access issues, coordinate systems, and support responsive models of service.

It is vital to ensure both the primary health (including dental) and chronic illness agendas, at both state and federal levels, specifically address the health needs of people living with severe mental illness. The interface between state and federal mental health funded programs and primary and chronic illness policy, programs and funding, needs to be conceptually mapped and practically built as a matter of urgency.

The PDRSS sector provides a critical and stable point of engagement for people living with severe mental illness and their carers. The sector offers a platform from which to build (or integrate) responses to health needs through targeted investment and partnership approaches.

VICSERV advocates for:

- Policy and funding support for an intelligent set of targeted, largely partnership-based strategies (described above).

- Recognition of and support for the potential of the PDRSS sector to play a key role in promoting heath responses and access to health services.

- Reform to funding through MBS that allows either block funding for primary health and chronic illness responses for this group or substantially incentivised payment schedules.

- Inclusion of a physical health focus and goals in the Victorian *Because Mental Health Matters* agenda.

VICSERV is committed to playing a leadership role and working in active, broad-based partnerships to ensure integrated health system reform that addresses the health needs of mental health consumers.

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Summary of proposed investments

Strategy Element	Initiative	Year 1	Over 3 Years	Funders	Outcomes
Research	Research partnership(s), prioritised agenda, seed funding	$150,000	To be determined	DHS and/or C'wealth	Better evidence of need, and impact; guide to effective practice
Practice Innovation	Pilot integrated PDRSS/ primary health responses (x 6 plus evaluation)	$1,950,000	$5,550,000	DHS Mental Health and Primary Care branches and/or explore potential partnership with C'wealth	Improved primary health response to target group, better linked sectors, good practice, evidence
	Targeted health promotion/prevention initiative	$100,000	To be determined	DHS with possible VicHealth partnership	Targeted health promotion model; enhanced consumer engagement, better linked sectors and extended partnerships
	Review of all PDRSS program types for 'whole of person health approaches'	Existing resources	Existing resources	VICSERV	Good practice evidence, gap analysis, better integrated program design
Workforce Awareness and Development	PDRSS sector Health Awareness Training Program	$40,000 plus existing resources	Existing resources	DHS/ VICSERV	Increased awareness and changed mindsets, improved health needs identification and better integrated PDRSS program design features
	Beyond Mental Illness Training Program for mental health clinicians and GPs	To be determined	To be determined	To be determined	Increased awareness and changed mindsets, improved health needs identification and service responsiveness

See also 'Targeted Policy and Investment' – MBS funding options (p. 4).

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Economic Participation: employment and education – changing outcomes - *Summary paper*

The evidence is in: employment and education are part of the solution![3]

It is time for increased and better coordinated investment and action that brings together employment, education and mental health agendas to deliver sustainable employment and education pathways for people living with severe mental illness. This will improve mental health and life outcomes.

Employment has been found to diminish symptoms, reduce hospitalisations, increase independence (including financial), improve self-worth and enhance social skills for people living with severe mental illness.

The benefits of employment flow beyond individuals to the wider community. In a work setting, personal contact with those experiencing mental illness can do much to counter myths and stigma.

Unemployment has been found to contribute significantly to the total cost impact of psychosis on the community. Conversely, people with psychosis who are engaged in meaningful activities (such as employment, study or other vocational roles) incur less expense for their condition than non-participants.

Increased participation in meaningful activities by just 10.0% of unemployed people with psychosis could potentially save around $147 million per annum; if the rate of participation increased by 30.0%, the savings would be around $441 million per annum.

The number of people with psychotic disorders who are employed increases proportionately with the number of secondary school completions, vocational qualifications, and degree qualifications.

The goal of realising a vocation in life—including, (but not exclusive to) being in a paid job—is a high priority for many people living with severe mental illness.

But our systems are failing to deliver

Workforce non-participation amongst people with psychotic disorders in Australia is more than 72.0%. The latest figures available through the Australian Bureau of Statistics (ABS) indicate that the unemployment rate amongst those with severe mental illness has increased in recent years to 19.5%. (The national unemployment rate at June 2008 was 4.2%.)

[3] Please refer to *Economic Participation: employment and education – changing outcomes, background paper* for details and references.

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People with psychiatric disabilities have the highest rate of workforce non-participation compared to other disabilities. They represent the largest disability group accessing disability employment services (at 30.0%) despite faring the worst in employment outcomes (both in securing and retaining work).

We know interruptions to education are due to the particular characteristics of illness onset, which typically occurs in early adulthood. Yet there is evidence of ongoing failure to act to minimise or address the impact of education disruption.

There is a demonstrable relationship between workforce non-participation and interrupted education. One study found 47.8% of the people living with severe mental illness had neither finished their secondary school education nor achieved post-secondary qualifications.

Barriers to employment (and education) are directly related to the symptom profile of low prevalence disorders and the side effects of anti-psychotic (and other) drugs. But there is evidence to suggest that the most significant barriers stem from inappropriate service provision, inadequate support, broader community beliefs and misconceptions about mental illness, as well as the marginalisation those with mental illness experience.

A job seeker with severe mental illness may need to access and coordinate three or more sectors across two levels of government. The challenge of navigating the system can be a profound barrier.

Mental health professionals can have low expectations of the vocational capacities of their patients, mirroring wider societal beliefs that those with psychiatric disabilities are unfit for work. Studies have shown that very few clients are asked about their vocational interests by their mental health workers.

We use some very 'blunt' tools in our program design

- The Job Capacity Assessment (JCA) can paradoxically act as a barrier to positive employment. Because of the episodic nature of serious mental illness, the JCA can under-estimate the assistance needs of job seekers (and refer them to inappropriate employment streams).

- Service capping, e.g. for the Personal Support Program (PSP), Disability Employment Network (DEN), and Vocational Rehabilitation Services (VRS), produces long waiting lists and discontinuity in service provision—both of which are counterintuitive to the rapid job searching approach of evidence-based early intervention approaches. Capping can also mean unsuitable referrals to Job Network. Once 'streamed', there is no easy way to be transferred or to access other programs due to capped places and administrative (bureaucratic) barriers.

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- There has been a profound tension between seeking assistance to 'find and try' employment and the risk to the (limited) financial security offered by the DSP.[4] Consumer concerns are further exacerbated by the need to retain a Health Care Card in order to afford essential medication and access low or no cost health services. The cost of pursuing education (HECS, IT and other expenses) can also be prohibitive. There has been no policy initiative that truly gives incentive and support to employment and education pathways for people living with severe mental illness.

- Many people with severe mental illness require longer-term supports to keep their jobs once the goal of gaining employment has been achieved. The current employment service system does not provide for such supports.

- Education and employment support initiatives lack a focused and proactive approach to working with employers and educational institutions to address stigma and support effort towards inclusion.

Hidden education and employment impacts: carers

On average, carers contribute over 100 hours per week caring for those with mental illness.[5] VICSERV is aware that the lives of carers are disrupted and impacted on by the carer and the demands that the episodic and enduring nature of severe mental illness can place upon them. The profile of carers is diverse and includes children, partners, siblings, parents and friends. Different phases and stages of their lives are affected, as carers undertake their role, including education and employment opportunities and outcomes. Yet there is no comprehensive body of knowledge about, or integrated approach to, supporting carers to address their vocational needs and goals.

It is time to recognise that…

The disruption to education and employment in the lives of carers contributes to the total cost burden of mental illness (personal and socio-economic).

Limitations of the mental health service system and the level of social exclusion experienced by people with severe mental illness impact heavily on the lives of carers. These impacts are most often hidden.

We need a sustained and coordinated effort to identify (make overt) and mitigate these costs whilst supporting the vital role carers play in the lives of their loved ones and the mental health service system.

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[4] In July 2008, the Federal Government decided to protect the incomes DSP job seekers. From September 2008, the assessment of pension eligibility will be separated from the assessment of employment assistance needs and people on DSP will be able to have employment assistance needs assessed without fear of losing income in the process. VICSERV supports and welcomes this decision as an important step in a broader process of developing inclusive policy.

[5] See *Social Inclusion – An Outcome Measure for the Mental Health Service System. Notes on Context, Definition and Evidence* for details.

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We have evidence about approaches that produce better employment outcomes

An approach that better integrates specialist employment services with mental health and Psychiatric Disability Rehabilitation and Support Services (PDRSS)—specialised supported employment or Individual Placement and Support—improves employment outcomes for 40-60% of participants. Features of specialised supported employment that make a positive difference to outcomes for people living with severe mental illness are:

1. Eligibility for employment services, based on consumer choice, not job readiness.

2. Integration of disability employment services with mental health care.

3. The goal of competitive or open employment.

4. Rapid commencement of job searching activities.

5. Job placements based on consumer preferences, strengths, experience, and interests.

6. Continuing support to retain employment.

7. Income support and benefits counselling.

8. Continuous availability of intensive onsite workplace support.

9. Multidisciplinary teams to coordinate treatment and vocational interventions.

10. Alliances between staff and consumers in rehabilitation.

11. Strategies to counter workplace stigma.

There is also emerging evidence that supported education programs (with comparable support features) work, and ultimately contribute to, improved quality of life and better employment outcomes.

From rhetoric to action: a rights-based, coordinated approach

Australia is a signatory to the United Nations *Covenant on Economic, Social and Cultural Rights*. We have committed to recognising the rights of everyone to opportunities to gain their living through work that is freely chosen, and to taking appropriate steps to safeguard these rights. It is time to make that commitment a reality for people who experience severe mental illness.

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There is a need for a specific education and employment policy and strategy (including investment) for people with serious mental illness that:

- Considers and responds to the nature of mental illness.
- Takes into account different age cohorts and related needs.
- Offers income security over extended time periods.
- Protects Health Care Card holder status and access to medication and health services.
- Addresses stigma.
- Coordinates and links education and employment support to mental health (clinical and support) responses.

The VICSERV proposition: targeted policy, immediate action[6]

There is a need for immediate action to address the barriers to employment and education experienced by people living with severe mental illness. There is a need for considered, integrated policy that focuses on the long term. It is also necessary to recognise and respond to the impacts of caring on the capacity for economic participation of carers.

The ageing of the population provides further imperatives to build more inclusive work environments and to increase the number and range of opportunities for people with mental illness to engage in meaningful work.

It is both important and timely to extend the body of knowledge about 'what works' in relation to effective employment and education programs for people living with severe mental illness and their carers, while remembering the different life stages and cohorts in each.

The VICSERV propositions involve a (necessarily) multi-faceted approach and suggest both immediate and longer-term actions. The propositions include:

[6] VICSERV is aware and supportive of the current (Commonwealth) review of employment services and will further develop and refine elements of this proposition in response to improvement and opportunities arising from this work.

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1. Long term: an effectively aligned approach achieved through targeted policy

VICSERV actively encourages the formation, by agreement of State and Commonwealth Governments, of a broad based working party to develop an integrated and coordinated *Education and Employment Policy/Strategy for People Living with Mental Illness.* The initiative must have the capacity to influence, over time, a broad range of departments, policies, systems and processes across jurisdictions in order to achieve better outcomes for people living with severe mental illness. It is important that this initiative incorporates or links to approaches that have been shown to be of value through work undertaken in the broader disability field. To make the necessary difference, however, this initiative must be specifically targeted to addressing the needs of people with severe mental illness.

Investment required: the initial investment is not in additional funds but in the dialogue and leadership necessary to build commitment and agreement to establishing a joint change agenda and working party. VICSERV will actively lend its voice and support to promoting a partnership between Commonwealth and State Governments and peak community and welfare organisations to build that agreement.

2. Actions to 'make a difference now'

Action 2.1 A new model of support

People living with severe mental illness who are attempting to engage in education/training or employment related activities require long-term, individualised support. Neither the PDRSS nor employment service sectors are currently geared up (or appropriately funded) to provide such support. Other than crisis services, mental health services are almost exclusively offered during business hours.

It is critical that the PDRSS sector is partly reoriented to recognise, encourage and support consumers to achieve their education and employment goals. This means extension of State-funded PDRSS (and/or selected Commonwealth initiatives) service hours to include after hours support options that are not crisis focused.

It is proposed that the Department of Human Services (DHS) Mental Health Branch and VICSERV work in partnership to further detail a conceptual model and indicative cost to inform a 'flexible hours support program' targeted toward consumers engaging in employment and/or education initiatives. There is potential for this work to feed into the proposed evaluation of the Commonwealth Personal Helpers and Mentors Program and, importantly, into current work on mental health service system reform in Victoria.

Investment required: $20,000 seed funding (and/or linkage to comparable work in progress). VICSERV will contribute in-kind research expertise to an equivalent value. This work should be initiated and completed within the shortest possible timeframe. It is anticipated that there will be a requirement to redirect and increase investment in the PDRSS sector. This will need to be linked to housing and education outcomes once the initial work is completed.

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Action 2.2 Building the peer workforce within the PDRSS sector

There is enormous potential to increase the peer workforce (people living with mental illness) in the PDRSS sector in the short-to-medium term. The benefits of a strong peer workforce include:

- Role modelling for consumers—confirmation of aspiration and hope.
- Provision of 'safe' initial employment pathways for people with severe mental illness.
- Better understanding of work environments and practices that are supportive of people with severe mental illness.
- Capture of evidence to challenge perception and stigma.
- Development of management and support models transferable to the broader (community) service sector.
- Learning for professionals working as colleagues and managers.

In order to achieve this type of workforce expansion, the PDRSS sector requires investment to:

- Support culture change and enhancement.
- Redesign (some) positions and structures.
- Enhance management and supervision skills.
- Foster, recruit and support additional peer workers.
- Evaluate effort over time—share good practice.

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VICSERV proposes piloting a *PDRSS Peer Workforce Initiative* in six selected sites across Victoria. Pilot sites are intended to reflect diversity within the sector and will receive organisation development grants (ODG) over a two-year period. ODG would be tied to:

- Specific 'peer' employment targets.
- Organisational change and development goals.
- Participation in longer-term evaluation.

There needs to be exploration of the issues of peers' rights to privacy and management of disclosure as part of developing and implementing the pilot. Evaluation of workplace changes within the pilot sites and the experience of peers is seen to be integral to the pilot and a means to promote longer-term change across sectors.

It is proposed that the pilot be a joint initiative of DHS and the Department of Planning and Community Development. There may also be potential to seek to Commonwealth contribution. VICSERV would seek to be actively engaged in the design of the pilot and would recommend strong engagement with consumer bodies with knowledge of peer workforce initiatives.

Investment required: $100,000 per pilot site per annum for two years ($1.2 million) plus $120,000 for pilot evaluation, ($1,320,000 over two years).

Action 2.3 Leveraged partnerships and better integrated responses

There is a need to better link employment services, mental health clinical services, PDRSS programs and employment services. This process can be assisted by 'better tools', including:

- Stronger emphasis on vocational goals in treatment and recovery plans. This approach could be actively fostered through Mental Health Alliances without additional investment.
- Funding and service agreement/contract inclusions that require demonstrated partnership and linkage between sectors. DHS could consider opportunities to achieve this as part of the *Because Mental Health Matters* policy development, however, broader change would need to be linked to the proposed *Education and Employment Policy/Strategy for People Living with a Mental Illness*. No additional investment is required.
- Job Capacity Assessment processes that allow for/encourage 'mental health' expert input into the types of support most congruent with consumers' experience of mental illness. This would require an agreed definition of the target group and mental illness. VICSERV is aware that current review processes at the Commonwealth level may provide useful forums where

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agreement on necessary change could occur. It would also be necessary to link this discussion to the question of expert resource availability and ensure state-based policy makers and clinical and support service providers are engaged.

Investment required: there is likely to be some additional investment required to ensure 'mental health' expert input is available in a timely manner. The extent and source(s) of funds/expertise would need to be determined through broad-based discussion, and the Commonwealth/MBS Mental Health Nurse initiative could be considered as an option.

3. Professional education and built capacity to address stigma in workplace/education settings

There are two aspects to this initiative

(a) '*Enabling employment and education' training* for mental health professionals, employment service providers and educators to assist in bringing about the attitudinal change across sectors necessary to ensure the effective inclusion of people living with severe mental illness in employment and education. The training would include the transfer of technical knowledge as well as challenge attitudes and myths that work against supporting people living with a mental illness to achieve their employment and education goals.

(b) It is proposed that VICSERV works in collaboration with members and selected providers (employment, clinical mental health, and education) to develop and pilot a training package and train-the-trainer modules over a 12-18-month period.

Investment required: $60,000 for training package(s) and pilot.

(c) *A proactive approach to working with employers to better understand mental illness and support workplace inclusion*

This initiative involves the two-year pilot of a 'Workplace Ready Team' including mental health and employment service professionals and consumer/peer workers. The team would work with a range of employers to support the active inclusion of people with a mental illness in the workplace and link those employers with employment services. The team would provide intensive assistance to an organisation for an agreed and fixed period of time offering staff and management education programs, assistance to design or redesign positions, and assistance in the development of workplace policies that support inclusion. The team would also explore the possibility of developing some from of 'inclusive practice award' program integrated into mainstream business awards events.

Investment required: two year pilot at $300,000 per annum (a total of $600,000). There is potential for this initiative to attract funding contribution from VicHealth and other bodies as well as from State and Commonwealth Government levels. The initiative may be designed to dovetail with other relevant workplace reform initiatives.

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4. Extending the evidence base for practice

VICSERV proposes two distinct research projects specifically designed to build the evidence base for practice. These are:

Project 1: Education: experience, aspirations and outcomes study

It is critical to develop a better understanding of the short and long term experience of people whose education trajectories are disrupted by mental illness in order to improve the timing and nature of supportive interventions. It is proposed to design and undertake an *Education: Experience, Aspirations and Outcomes* Study involving a significant-sized group of mental health consumers of both clinical and PDRSS services (in Victoria) who represent a diversity of the 'illness' experience, as well as an age, gender and cultural mix.

The study will explore the impact of mental illness on the consumers' educational experiences, as well as on education outcomes and the consequent impact on employment. It is intended that this study involve collaboration between consumer representatives, clinical service representatives, DHS and VICSERV (and its members). It is likely to be of additional value to engage representatives of other (relevant) Government departments as well as employment service provider peak bodies to a Project Reference Group. It is expected a credible research body would be contracted to design and undertake the research.

Investment required: $30,000 to deign the research and an additional $90,000 to complete the project. It is anticipated the work could be completed within a 12-18-month timeframe.

Project 2: Impact study of caring on employment and education

The impact of caring for people living with severe mental illness on the employment and education opportunities and outcomes of carers is an issue that is neither adequately understood nor responded to. Given the range of people engaged as carers—children, partners, siblings, parents and friends—VICSERV proposes a staged approach to understanding and responding to the impact.

Initial effort would include building a partnership of the diverse group of stakeholders able to bring the necessary breadth of knowledge and awareness to the table to scope a viable research project (including literature review). VICSERV proposes partnering with selected peak organisation(s) and DHS to initiate this work.

Investment required: $60,000 in Year one to build the research partnership, complete the necessary literature review and scope/design the research. The full requirement for investment would be identified in Year one.

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Summary of proposed investments

Strategy Element	Initiative	Year 1	Over 3 Years	Funders and Contributors	Outcomes
Targeted Policy	Education and employment – inter-sectoral alignment, targeted policy and strategy	No additional resources, commitment leadership and dialogue	Not known	Leadership + participation at C'Wealth and State levels	An aligned change agenda that supports education employment outcomes
Actions to Make a Difference Now	New model of support: 'flexible hours support program'	$20,000 in seed funding, VICSERV in-kind contribution (equivalent value)	To be determined	DHS Mental Health Branch and VICSERV	Tailored support model that enables consumers to achieve better education and employment outcomes
	Peer workforce	$100,000 x 6+ $60,000 (evaluation) = $660,000	(Year 2) $100,000 x6 + $60,000 (evaluation) = $660,000	DHS, DPCD, VICSERV (and members) and others	Expanded peer workforce, good (OD) practice models
Organisational Capacity Building	Training Program: Enabling Employment and Education	$60,000	-	VICSERV and members, selected providers	Attitudinal change amongst professional and a training resource for ongoing use
	Workplace Ready Team	$300,000	$300,000	C'wealth and State Governments VicHealth, VICSERV, Employment Services	Increased number of employers, committed and ready to provide sustainable employment for consumers
Evidence-Based Practice	Education: Experience, Aspirations and Outcomes Study	$30,000 to design	$90,000 to complete	DHS, VICSERV, consumers and others	Increased understanding of how to build capacity for better educational outcomes
	Impact Study of Caring on Employment and Education	$60,000	To be determined	DHS, VICSERV and Carer organisations	Increased understanding of the impacts of the role of carer on education and employment

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Housing and Support: a platform for recovery
Summary paper

Mental health service consumers repeatedly tell us…[7]

… That stable housing is critical to the quality of their lives, and support to retain that housing is the most important issue they are faced with.

We know the housing need; we have the evidence for practice

It is time for planned investment and action that brings together mental health and housing agendas to deliver 'homes' for people with severe mental illness.

- At least 42.0% of people with severe mental illness are currently *housed in tenuous forms of accommodation* such as hostels, boarding houses, hotel/rented rooms, emergency accommodation, shelters, no fixed address. It is likely that many are cycling through different types of tenuous housing and primary homelessness ('sleeping rough'). The movement through tenuous housing and primary homelessness—and the repeated loss of stable accommodation—is captured by the concept of *iterative homelessness*.

- Research shows that two-thirds of consumers identify *housing and housing support* as the most important issues in their lives.

- There is a strong association between housing and clinical improvement. Stable housing has been shown to be a better predictor of reduced hospital admissions than clinical interventions.

This story is not new. In 1993, the *Report of the National Inquiry into the Human Rights of People with Mental Illness*, stated:

> *One of the biggest obstacles in the lives of people with mental illness is the absence of adequate affordable and secure accommodation. Living with a mental illness – or recovering from it – is difficult even the best circumstances. Without a decent place to live it is virtually impossible.*

We know the barriers to housing

- Public debate on affordable housing has a strong focus on home ownership and working families. The reality is that most people living with severe mental illness are far removed from the possibility of home ownership. Only 27% of people with psychiatric disability are buying their own homes compared to 70% of the mainstream population.

[7] Please refer to *Housing and Support – Policy and Practice Failure. Background Paper* for details and references.

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- Housing supply is insufficient. Private rental is becoming increasingly out of reach of people living with severe mental illness. The supply of public and community housing is inadequate with successive governments over a number of years failing to properly resource the social housing sector. Between 1996 and 2005, the *Commonwealth Government stripped more than $3 billion from funding to social housing*, despite significant increases in the need for affordable rental accommodation due to upward trends in the housing market.

- There is no systematic policy or plan for developing and maintaining an adequate stock of housing or for a flexible, supported housing program with state-wide coverage that directly addresses the (changing) needs of people living with severe mental illness. We appear to be spending a disproportionate amount on 'housing' people in hospitals (or prisons).

- For people with a severe mental illness, housing means affordable and appropriate accommodation, plus the supports necessary, to maintain tenure. Yet there is no overarching and consistent approach to providing housing linked support that meets the changing needs of these consumers.

- People living with severe mental illness are often 'invisible' in 'ageing in place' policy and program initiatives.

- There is *inadequate linkage* between mental health and housing policy and planning agendas.

We know what works

Stable, affordable, (individually) appropriate housing options with flexible support. Key features:

- Housing policy and options with an explicit focus on people recovering from severe mental illness

- The provision of secure and ongoing tenure in appropriately designed and located housing stock

- Housing options that are integrated into the community in a manner that addresses stigma

- Choice of housing based on consumer preference e.g. a 'home', over which consumer control is fostered

- Comprehensive and coordinated ongoing support tailored to individual needs as they change over time—provided in the person's home (rather than in a transitional environment)

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- Eligibility for housing based on need and de-linked from compliance and wellness requirements.

We know there are *cost savings* to be made in a range of areas including clinical, emergency and crisis services through the provision of stable, appropriate housing that comes with long-term support.

Addressing housing and support needs: turning knowledge into action together

The *needs of people living with severe mental illness for stable, appropriate 'homes' must be addressed if we are serious about supporting recovery* and maximising the positive impact of Psychiatric Disability Rehabilitation and Support Services (PDRSS) and clinical interventions on that journey. To successfully meet housing needs it is necessary to:

- Respond to the diversity of the population of people living with severe mental illness, taking into account age, gender, capacity, culture, relationships, and preferences

- Remove any requirement for 'wellness' from housing eligibility requirements

- Address stigma

- Ensure the supports to maintaining housing are flexible and readily available

- Make housing and support 'everybody's business'

- Invest in the short, medium and long term.

There are important opportunities to progress a *specific housing agenda* for people living with severe mental illness at both State and Commonwealth Government levels by:

- Actively participating in and influencing affordable housing policy directions and initiatives

- Ensuring mental health policy and practice developments address the critical issues of flexible (housing) support

- Promoting strong inter-sectoral linkages and partnerships that actively promote shared approaches and joint accountability for achieving housing outcomes.

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Carers as housing and support providers

Carers can spend over 100 hours a week providing care for people with mental illness.[8] Their role is hidden or underestimated in many ways, and this is largely the case when in comes to providing housing and support options for their care recipients. Carers are housing and support providers, and they provide these in the long and short term, as well as in planned and emergency contexts. The extent of the role of carers in these capacities is not well understood, and there are emerging risks and vulnerabilities as some carers age and others face their own housing affordability issues.

It is critical to build a comprehensive knowledge of the part carers play in responding to the housing needs of people with mental illness. This will enable us to better understand their risks and vulnerabilities and provide adequate and appropriate supports to ensure sustainability of this 'hidden' housing sector.

At the present time, and in this paper, VICSERV is not fully addressing the issue through the propositions offered, but does seek to ensure it is on the mental health reform 'radar'. VICSERV plans to undertake a more detailed analysis of carer contributions, roles and needs in its next phase of proposition development and invites interested stakeholders to engage in dialogue and a partnership approach to this work.

The VICSERV proposition: making housing and support 'everybody's business'

A respect for human rights and practice evidence combine to underscore the critical importance of responding to the housing and related support needs of people with severe mental illness is a matter of priority. The failure to respect these rights and meet these needs harms consumers, limits potential, and exacerbates and undermines the value of public investment in treatment and other services.

In order to effectively support recovery, VICSERV proposes a multi-faceted housing strategy that will turn knowledge into action and, ultimately, produce better life outcomes for consumers. The strategy requires a commitment to partnering across sectors and for intervening at policy, planning and service delivery levels to make housing 'everybody's business'.

There are *three strategy elements* in the VICSERV proposition. These are:

- Visibility and voice
- Planned and integrated approach
- Innovation and expansion.

[8] See *Social Inclusion – An Outcome Measure for the Mental Health Service System. Notes on Context, Definition and Evidence* for details.

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Visibility and voice

There is a risk that the specific, yet diverse needs of people living with severe mental illness will 'get lost' and become diluted in the broader affordable housing and homelessness debates. Whilst these debates are relevant and important for mental health consumers, there is a risk of their needs being overshadowed by the needs and issues of other (more dominant) groups, or being only partially recognised and responded to.

It is therefore important to establish a specific 'mental health housing and support agenda' that is interlinked to homelessness and affordable housing policy and initiatives as well as mental health policy and service system development, at both federal and state levels.

To achieve and sustain this 'voice' and influence, VICSERV proposes series of three short to medium term initiatives aimed at quantifying and making need explicit (and at promoting) evidence-based housing and support solutions. These initiatives are:

(a) Economic modelling of costs/benefits of stable housing. It is proposed that a project is initiated to investigate economic modelling of the costs/benefits of stable housing and its relationship to recovery. This project will include a literature review and (extended) research study. The project could usefully be supported by a collaborative approach involving:

Government as co-leader, (part-) funder and partnership broker.

VICSERV as sector agent and co-leader.

Representation from consumer bodies, clinical mental health services, and the housing/homeless sector.

It is envisaged that a highly credentialed research body would be contracted to finalise a research methodology and undertake the research based on the scope identified by the stakeholder/research partnership. The initial literature review would provide information on housing options that are appropriate and economically viable and evidence of the impact of housing on recovery goals.

Investment required: $60,000 in Year One to develop the research scope and proposal and complete the literature review. It is expected that longer-term requirements would be identified as part of the scoping work.

(b) Ageing carers and housing risk. There is an important area of 'housing risk' that is currently not quantified or managed—the risk to consumers who are living with aging carers. It is proposed that VICSERV be specifically funded to work though its member agencies to identify the extent of the risk and options for addressing it.

Investment required: once-off, specific purpose funding to VICSERV of $60,000.

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(c) Discharge to where?There is a relatively cost-effective and straight-forward option for gaining a broad 'snapshot' of housing need and appropriateness of current housing options. The method uses bed-based services to administer a tight set of questions related to housing options and preferences—including the actual accommodation the consumer is discharged to. The questions would be embedded in discharge planning and discharge records for a limited time period. The 'snapshot' could be taken on a state-wide basis (preferably) or in selected local areas, potentially using Mental Health Alliances as research champions.

It is proposed that this research project be designed and implemented at the soonest possible time and be jointly developed by the Department of Human Services (DHS), VICSERV and Area Mental Health Services representatives.

It is intended that the findings from these initiatives are actively utilised by the DHS, VICSERV and its members and partners to influence and inform federal and state housing and mental health agendas to incorporate specific and explicit housing strategies for people living with severe mental illness. Findings may also inform the work of Mental Health Alliances.

Investment required: it is anticipated that this work could be resourced from within the DHS Mental Health Branch with the support of Mental Health Alliances, although there may be some cost associated with question design and collation and analysis of results.

Planned and integrated approach

Recognising the critical role of secure housing and support to retain housing in recovery and optimising the value of clinical interventions means taking a proactive, planned approach to ensuring that housing (and housing need) is 'everybody's business'. VICSERV is proposing multi-level strategy to achieve this. The strategy includes:

(a) Housing needs forecasting: In order to meet housing needs in the long term and move from inadequate, reactive responses, it is essential to plan to meet needs by developing a sound understanding of its parameters. The first step is to complete a 'housing needs forecasting' project that considers the immediate, medium and longer term (based on burden of disease and population projections) housing and support needs for people living with severe mental illness. It is proposed that the partnership group identified to lead and support the 'economic modelling' project (see above) be utilised to scope and initiate this work.

Investment required: $120,000.

(b) Opportunity audit: It is recognised that addressing gaps in housing stock requires long-term strategies and solutions, however, it is possible to identify immediate and medium opportunities that are worth investigating. There are properties that are land owned,

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utilised by, or accessible to PDRSS providers that could be converted though capital investment into housing stock in relatively short timeframes if process obstacles are addressed.

An audit of these opportunities and the barriers to converting them into innovative housing solutions provides a sound basis for short-medium term planning. It is proposed that VICSERV work with its members to compete the 'opportunity audit' in a project jointly funded by DHS Mental Health and Housing Branches. VICSERV would expect to involve a community housing provider/expert in the project planning and implementation.

Investment required: once-off, specific purpose funding of $75,000.

(c) Housing and support on Mental Health Alliance agendas. It is important that VICSERV, through its members, and DHS, through its policy and funder roles, work to ensure that Mental Health Alliances include 'housing and support' needs analysis and responses as part of their program of work directed towards improving client focus and better (clinical) outcomes.

Investment required: no additional.

Innovation and Expansion

(a) Scalable, flexible models of housing linked support. In order to make a difference to outcomes for mental health consumers and achieve a mental health service system that is not driven by crisis, exacerbated by housing insecurity, or blocked by housing shortage, there is no option but to invest in creating and maintaining homes for people living with severe mental illness. Homes are about both appropriate housing stock and flexible models of support.

Investment required: It is vital to radically expand the investment in home-based support options increasing the reach of these programs and increasing capacity to scale up and scale down support to individual consumers depending on their needs at different points in time.

Specifically, response capacity must be increased (in the shortest possible timeframes) to address the extent of need for housing linked support. This means meeting demand for support in terms of number of individuals requiring support and the frequency of support required. Programs must be funded to provide some level of coverage after hours (including weekends). Continuity of relationship with clients (from community to acute or other bed-based services and between community locations in agreed local areas) should also be promoted. This must be done without programs becoming crisis responses. This means substantial investment in the PDRSS sector in housing linked

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support initiatives using a unit price/funding model that adequately meets costs and provides for planned out-of-hours inputs.

In order to determine the quantum of the required investment over time, it is necessary to adequately assess (and forecast) the degree and nature of need and fully conceptualise the model of service. This work involves a different mindset—one which recognises that clinical outcomes will be improved as housing and housing linked support needs are met.

VICSERV proposes the initiation of a staged modelling project that initially (and in the shortest possible timeframe) uses existing understanding/evidence of unmet or inadequately met needs and good practice evidence to inform the first phase of increased investment. A long-term investment plan would then be developed built on knowledge from:

- Economic modelling of cost/benefits of stable housing (see 1(a) above).
- Housing needs forecasting (see 2(b) above).
- 'Discharge to where?' research (see 2(c) above).

The plan would be based on consideration of potential alignment between (some) State (e.g. HBOS) and Commonwealth (e.g. PHAMS) funding streams, other relevant opportunities and information. VICSERV recognises and supports the DHS role in leading this process and seeks to be an active contributor throughout both phases.

(b) Workforce needs analysis: It is critical that Victoria, as part of creating its vision for community mental health into the future, incorporates a workforce strategy that assists in rebalancing the workforce structure. This rebalancing would reflect the fact that an effective, outcome-driven mental health service system is as much about addressing social risk and protective factors (particularly those related to housing and support) as it is about clinical risk and clinical intervention.

The Ministerial Mental Health Workforce Advisory Group has an important role in conceptualising a workforce based on a different paradigm and models of community care that focus on meeting support needs in order to maximise the gain from clinical inputs. There is a risk that the workforce planning agenda could be dominated by clinical workforce shortage and a consequent need to ensure inputs (beyond representational roles) that effectively raise the broader conceptual questions and workforce issues.

VICSERV seeks the opportunity to address the Advisory Group on this matter using the evidence and propositions in this paper (and those contained in the companion papers which together form the *Pathways to Social Inclusion*). VICSERV will also further develop its own workforce needs over the upcoming 12 months.

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Investment required: whilst there is a requirement for substantial investment on building the housing support workforce, there is no immediate investment required in workforce needs analysis beyond the existing commitment to the Advisory Group, providing the focus of the work undertaken through that forum has adequate breadth. VICSERV's own work will be internally resourced.

(c) Capital investment for innovation and to meet housing need: it is clear that there is requirement for large-scale investment in housing options for people living with severe mental illness. The quantum of the required investment will be determined as need and models that work are better quantified and the affordable housing agenda becomes specifically concerned with and inclusive of this client group (see propositions above).

(d) 'Limited life (Social Housing) Subsidy Scheme': for the medium term, until adequate levels of appropriate housing stock are achieved, it is inevitable that significant numbers of people with a mental illness who are 'Segment 1 eligible' will continue to live in tenuous accommodation types, i.e. very low-end private rental, boarding houses, pension only Supported Residential Services (SRS), caravan parks etc. This market can be termed the 'social housing market'. Whilst these options are not necessarily preferred or desirable, there is an immediate need to make them affordable and more stable in order to meet the needs of consumers. This means consideration of a 'limited life social housing subsidy scheme' with the level of subsidy potentially being higher than 50% of rental cost.

VICSERV is aware that this issue is a complex and vexed one and recognises detailed work will need to be undertaken to ensure the proposed subsidy does not result in unintended consequences (harmful practice), and is not seen to substitute for the central, longer-term goal of affordable, appropriate housing stock.

Investment required (c) and (d): the investment analysis for these propositions is beyond the scope of VICSERV. However, the key messages related to investment are:

- It needs to be planned and upfront.
- It needs to respond to the immediate crisis with shorter-term programs of investment through targeted subsidy.
- The longer-term economic gains and health outcomes will justify substantial levels of investment in housing that are required.

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Summary of proposed investments

Strategy Element	Initiative	Year 1	Over 3 Years (& beyond)	Funders and Contributors	Outcomes
Visibility and Voice	Economic modelling	$60,000	To be determined	Seed funding DHS, longer term to be determined	Evidence base for investment
	Ageing carers and housing risk	$60,000	-	DHS or C'wealth	Risk identified and understood
	'Discharge to where?' snapshot	Existing	-	VICSERV/ DHS	'Quick' overview of immediate need
Planned and Integrated Approach	Housing needs forecasting	$120,000	To be determined	DHS	Knowledge of need over time. Capacity to take a planned approach
	Opportunity audit	$75,000	-	DHS	Viable opportunities identified and scoped
	Mental Health Alliances – focus on housing and support	Nil	-	Existing forum and resources	Increased awareness, local responsiveness
Innovation and Expansion	Housing linked support	To be determined	To be determined	DHS – potential C'wealth partnership	Rebalanced system – better consumer outcomes
	Workforce needs analysis	Existing	-	Ministerial Advisory Group, DHS, VICSERV	Balanced and effective approach to workforce planning
	Capital investment for innovation and to meet need	To be determined	To be determined	C'wealth, State, housing providers	Long term solution and platform for recovery in place – better outcomes
	Limited-life social housing subsidy scheme	To be determined	To be determined	DHS, C'wealth, others	Current crisis responded to in the short –medium term

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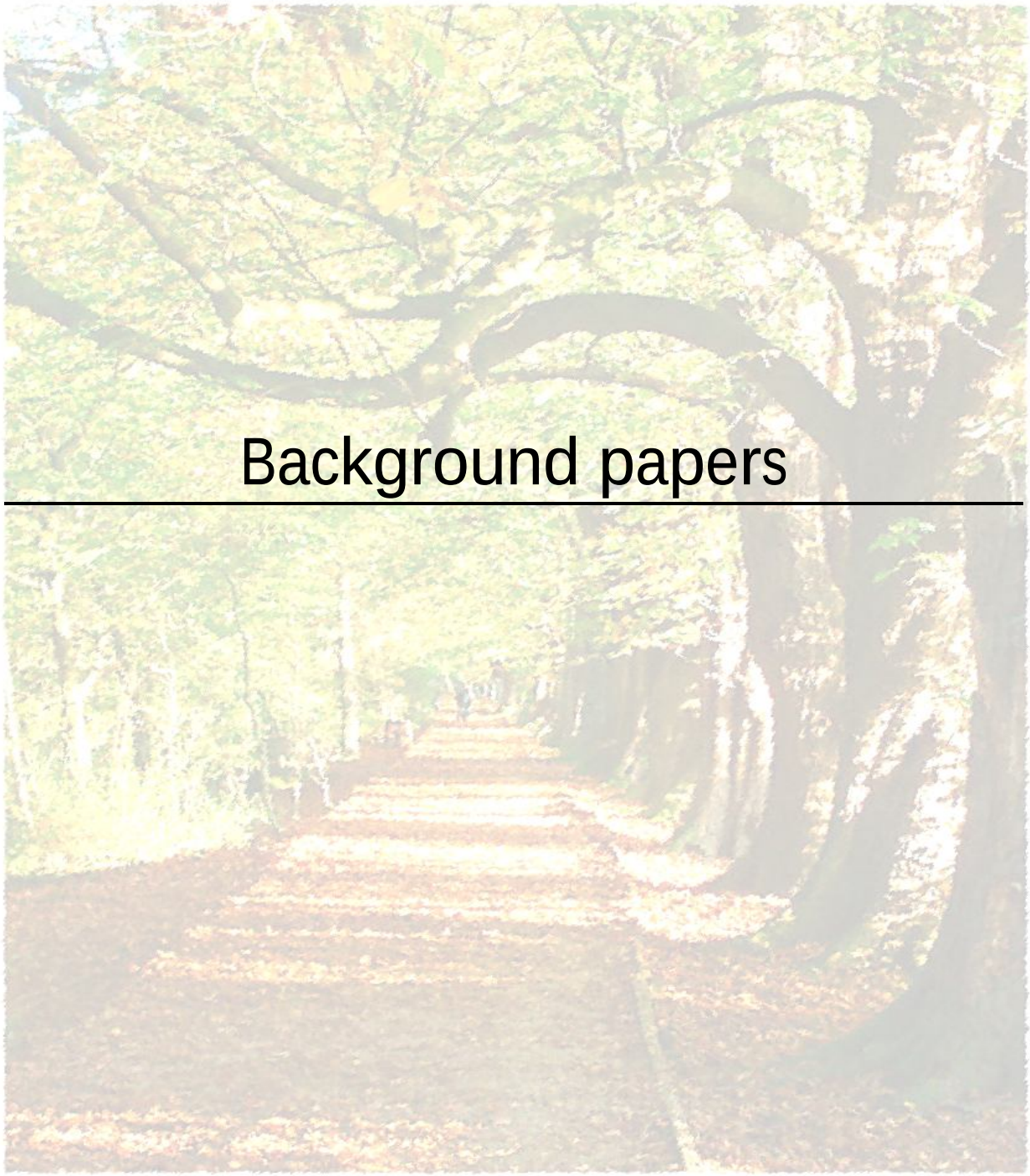

Background papers

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Social Inclusion: an outcome measure for the mental health service system - *Background paper*

Recent directions and initiatives

United Nations Convention on the Rights of Persons with Disabilities

In July 2008, Australia became one of the first nations to ratify the *United Nations Convention on the Rights of Persons with Disabilities*. The Convention recognises that if the rights and freedoms of individuals enshrined in the *Universal Declaration of Human Rights* are to be truly universal, then they must be inclusive of people with disabilities—including those with psychiatric disability. Signatories to the Convention agree to promote communities in which all people with disabilities are included as equal and active citizens.[9]

Federal Social Inclusion Board

This recently created cabinet-level committee provides expert advice to the Minister for Social Inclusion and the Prime Minister to help progress a social inclusion agenda. The agenda hopes to increase opportunities for participation amongst those who are most marginalised and excluded from mainstream society. Early priorities include responding to the employment needs of people with disabilities (including those living with severe mental illness) and addressing the incidence of homelessness. It is also hoped that the social inclusion agenda will usher a 'new era of governance' that will see governments at all levels—federal, state/territory and local—working together and across different departments to shape policies and deliver services necessary for greater inclusivity.[10]

South Australian Social Inclusion Unit

Since 2002, the South Australian Government has had a Social Inclusion Unit to address a range of social issues stemming from exclusion, such as homelessness and problematic drug use. The Unit is accountable directly to the Premier. Its agenda encompasses initiatives and priorities that sit in several departments but are unified through a single vision of an inclusive society. In 2005, the Unit was given the responsibility of reforming the state's mental health service system in recognition that people living with mental illness often experience the most extreme forms of exclusion.[11]

Victorian initiatives

(a) *Because Mental Health Matters: A New Focus for Mental Health and Wellbeing in Victoria*. This consultation paper, produced for the review/reform of Victoria's mental health service system, identifies a number of issues since de-institutionalisation, such as the lack of respect, dignity, involvement and control given to consumers in some parts of

[9] More on Australia's signing of the Convention can be found at: http://www.hreoc.gov.au/disability_rights/convention.htm.
[10] More on the social inclusion agenda and Board can be found at: http://www.socialinclusion.gov.au/.
[11] State Government of South Australia (2006) *Stepping Up: A Social Inclusion Action Plan for Mental Health Reform 2007 – 2012*, Adelaide: South Australian Government Social Inclusion Board.

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the sector.[12] Importantly, the paper acknowledges a growing concern for the poor treatment of people with mental illness in other spheres of life including housing, employment, education, and a myriad of day-to-day aspects of community and neighbourhood living.

In recognition of the link between these spheres of life and mental health outcomes, the paper makes a claim for mental health service reform together with a strengthening of social inclusion efforts for people living with mental illness – here building on the Victorian Government's key social policy platform to address discrimination, marginalisation, exclusion and inequalities as outlined in *A Fairer Victoria.*[13] Service reform, in parallel with social inclusion initiatives, would see stronger linkages between different parts of the mental health service system (e.g. clinicians and the PDRSS sector) as well as across different government departments and service sectors:

When the person is acutely unwell, the role of the clinician should be emphasised. As the person's symptoms stabilise, that emphasis should shift to the provision of psychosocial supports (including PDRSS), with a focus on improving the person's daily living skills and addressing any broader health and welfare issues that may be impacting on their recovery, such as housing, connection to family and culture, and meaningful activities that promote social inclusion.[14]

(b) *Charter of Human Rights and Responsibilities*. The Charter enshrines the intrinsic value of an inclusive society free from discrimination, and there are now obligations on all public authorities to comply with a rights-based agenda to social inequalities: a first for any Australian jurisdiction. Victoria also expects to review the *Victorian Mental Health Act 1986* during the next two years to ensure it provides an effective legislative framework for mental health services in light of the Charter.

(c) *Victorian Health Promotion Foundation (VicHealth) Research and Activity*. VicHealth has extensively explored social inclusion as a key determinant of mental health and wellbeing.[15] Social inclusion is a named program area within the VicHealth agenda, and the organisation currently collaborates with a range of partners across sectors to promote inclusive societies as a counter to discrimination, marginalisation and exclusion.

Three meanings: which one?

There are at least three meanings that can be attributed to the term, social inclusion.[16] The originating meaning—used by the Blair Government in the UK—sees social inclusion as the solution to marginalisation, disadvantage and inequality in society. This meaning places social inclusion within a human rights and equity agenda; and sees an explicit role for governments to

[12] State Government of Victoria (2008) *Because Mental Health Matters: A New Focus for Mental Health and Wellbeing in Victoria*, Consultation Paper, Melbourne: Victorian Government Department of Human Services.
[13] State Government of Victoria (2008) *A Fairer Victoria: Achievements So Far,* Melbourne: Victorian Government Department of Premier and Cabinet.
[14] State Government of Victoria, (2008) *Because Mental Health Matters*, op. cit. p.
[15] Victorian Health Promotion Foundation *Mental Health Action Plan* available at: www.vichealth.vic.gov.au.
[16] Scanlon C (2008) 'Lessons for Rudd as social inclusion moves to top of agenda' in *newparadigm*, Autumn, pp. 10-11.

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put into place actions that will remove barriers and foster participation by all citizens in the social, economic, institutional and symbolic fabric of life.

The second meaning of social inclusion regards it as an individual responsibility, with those left out due to their own failings. The third meaning defines social inclusion as social integration or cohesion (i.e. communities getting along). The second meaning is devoid of the focus on inequalities that comes with the first meaning; and whilst the third meaning has a lovely aspirational sound, it can drift into something like the second meaning – this time by leaving it up to individuals in communities to cohere simply by being nicer to each other. Integration/ cohesion is good; the trick is to keep the aspiration close to the social justice goal of a fairer society.

The meaning of social inclusion that best serves people with severe mental illness is the original one, with the understanding that the third definition also has a place as long as it doesn't stray from a social justice platform. This is because the lives of people with severe mental illness are characterised by a significant compounding of disadvantage that creates exclusion on a number of fronts; and unless we address these facets of exclusion through coherent policy and an integrated service system response, this group will never experience true social inclusion.

The five facets of exclusion: [17]

1. *Relational Exclusion:* refers to poor social ties or connectedness. Sites of relational exclusion include the family, neighbourhood, workplace/vocational setting, and wider community.
2. *Economic Exclusion:* refers to lack of resources (wages and income support) and the capacity to consume goods and services.
3. *Institutional Exclusion:* the result of inequitable access to a range of institutions such as justice, education, health and welfare.
4. *Geographic Exclusion:* refers to spatial clustering of people in specific locations or neighbourhoods. Disadvantaged groups, for example, can be housed in specific areas, institutionalised, detained or incarcerated.
5. *Symbolic Exclusion:* refers to poor/low sense of belonging, purpose, agency, identity, future and hope.

Evidence of exclusion

After 25 years of de-institutionalisation, three national mental health plans, and a national inquiry into the rights of people with mental illness, people with serious mental illness experience levels of exclusion that suggest 'institutionalisation' in a different form.[18] As noted by the Mental Health Coordinating Council (MHCC), when discharged into the community 'consumers can find themselves in conditions comparable to those in institutions, either literally

[17] These facets are drawn (and slightly modified) from Robinson, C (2003) *Understanding Iterative Homelessness: The Case for People with Mental Disorders*, Melbourne: Australian Housing and Urban Research Institute, p. 13.
[18] More on the most recent Council of Australian Governments' *National Action Plan on Mental Health (2006-2011)* can be found at http://www.health.gov.au/coagmentalhealth. The *Report of the National Inquiry into the Human Rights of People with Mental Illness* (1993) – also known as the Burdekin report – can be found at http://www.hreoc.gov.au/human_rights/mental_illness/index.html.

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(in prison or sub-standard housing) or figuratively – including isolation, discrimination and hopelessness for the future.'[19] Statistics show that the business of de-institutionalisation is far from finished. People with severe mental illness:

- Are unemployed (economic exclusion): The most recent unemployment figure for this group puts it at 19.5%, compared to 4.2% for the overall population.[20]

- Have low levels of educational attainment (institutional exclusion): 47.8% have not finished their secondary school education or achieved post-secondary qualifications.[21]

- Are dependent on welfare support (economic exclusion): 85.2% receive a government pension or social benefit (in particular, the disability pension) as their main income source.[22]

- Experience iterations of homelessness (geographic exclusion): 19.6% are in institutional settings, 13.6% live in hostels, and 8.8% live in other marginal housing (e.g. boarding houses, rented rooms, crisis accommodation, shelters) or are amongst the primary homeless.[23]

- Experience barriers to mainstream health services (institutional exclusion): A fragmented and disjointed health service system means that people's physical health needs are commonly overlooked either until a medical emergency occurs, or it is too late. People living with severe mental illness have an overall health status that is far lower that the mainstream population resulting in significant health inequalities. The death rate of people with mental illness is 2.5 times greater than that of the general population, which is equivalent to a life expectancy of 50 to 59. People with schizophrenia have a mortality rate that is up to three times higher than that of the general population.[24]

- Have difficulties building and maintaining social ties (relational exclusion): 31.3% live alone in single-person households and only 9.3% have a person at home they can describe as a carer (most often a mother or partner). Around 84.1% are single, divorced, separated or widowed. Some 47.1% report not sharing meals with others; 40.0% do not watch television with others; and 39.8% do not do chores or run errands with others. In terms of friendships, 39.1% report having no 'best friend' with whom they can share thoughts and feelings and 44.9% feel they need 'good friends' in their lives.[25]

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[19] Merton R and Bateman J (2007) *Social Inclusion: The Importance to Mental Health*, Roselle, NSW: Mental Health Coordinating Council, p. 19.
[20] See *Economic Participation: Employment and Education – Changing Outcomes. Background Paper* for details.
[21] Ibid.
[22] Ibid.
[23] See *Housing and Support – A Platform for Recovery. Background Paper* for details.
[24] See *Health Inequalities – Policy and Practice Failure. Background Paper* for details.
[25] Jablensky A, McGrath J, Herrman H, Castle D, Gureje O, Morgan V and Korten A (1999) *People Living with Psychotic Illness: An Australian Study 1997-98*, National Survey of Mental Health and Wellbeing Report 4, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing. This study was part of the first National Survey of Mental Health and Wellbeing. The second National Survey of Mental Health and Wellbeing was conducted in 2007 with preliminary results available in late 2008.

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- Are over-represented in the criminal justice system (institutional exclusion): the 12-month prevalence rate of psychosis in the prison population is 9.0%, which is 30 times higher than the non-prison population.[26]

- Are stigmatised and feel the effects of discrimination on a daily basis e.g. relational, economic, institutional, geographic and symbolic exclusion. (See below.)

- Have a low sense of belonging, agency and purpose - symbolic exclusion. (See below.)

Stigma – both cause and symptom of exclusion

Stigma means to be marked by others as shameful. To be stigmatised is to be disgraced and disapproved by others—and to a certain extent to internalise their views (to become the 'disgraced' etc.) Historically, mental illness has generated misunderstandings, misconceptions, myths and fear in the community. These have made it all too easy for others to stigmatise people with mental health issues and to keep them at the edges of society.

When asked about what things would make the biggest difference in their lives, people affected by severe mental illness say reducing stigma.[27] Indeed, many report that living with stigma is worse than having a mental illness.[28] Carr and Halpin note that stigma has a huge bearing on the quality of life of consumers. Drawing on an extensive body of literature, they write:

> *Stigma promotes and reinforces social isolation, limits equitable opportunities for employment and recreation, discourages treatment-seeking by those who need it, creates, reinforces and sustains pseudo-psychiatric mythology, and is frequently internalised by people with a mental illness resulting in much suffering.*[29]

Because stigma is so widespread in the community, the mainstream population is often reluctant to engage with people who have severe mental illness – thereby further perpetuating misconceptions about mental illness. In this sense, stigma leads to a range of relational exclusions from family and neighbourhood/community networks to places of study and employment.

When myths about people with mental illness are circulated in the workplace (e.g. that they are unfit for work) then this can mean employers are reluctant to employ them. In this sense, stigma has a direct bearing on economic exclusion. When fears about people with mental illness exist in the housing sector (e.g. that they are inherently violent, dangerous or untrustworthy) then this

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[26] See *Housing and Support – A Platform for Recovery. Background Paper* for details.
[27] Research by SANE Australia as cited in Carr V and Halpin S (2002) *Stigma and Discrimination*, National Survey of Mental Health and Wellbeing Bulletin 6, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing, p. 1.
[28] Commonwealth of Australia (2005) 'Challenging stigma', Response Ability Project, Australian Government Department of Health and Ageing, available at http://www.responseability.org/client_images/33762.pdf and accessed 31/07/08.
[29] Carr and Halpin, op. cit., p. 3.

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can make it hard for consumers to obtain accommodation in their place of choice. This is how stigma relates to geographic exclusion.

When beliefs about people with severe mental illness are held by institutions such as health, justice, welfare and education (e.g. that they have low aspirations in life or their physical health needs are not important) then this can mean that our very systems fail to support those most in need. This is how stigma relates to institutional exclusion.

All of this can leave consumers feeling shamed, disgraced, humiliated, ostracised, despairing, hopeless, disenfranchised, and in a state of 'not belonging' – or in other words: symbolically excluded.

Social inclusion and recovery

Social inclusion is good for recovery. Recovery is grounded in principles of empowerment and self-determination.[30] It refers to the re/gaining of control of one's life by learning to manage mental illness and its impacts. It does not mean cure, since many symptoms of mental illness can remain and there may be relapses and struggles with the illness again. For many, what is recovered is a sense of self and purpose, a way of living with the illness (its ebbs/flows and non-linearity) rather than being defined or controlled by it. In other words, a sense of being that enables a new relationship with self and community. Recovery is often described as a 'journey' towards greater participation and citizenship.

In Victoria, the PDRSS sector plays an important role in the journey of recovery of consumers. PDRSS provide specialist support services to people with significant impairment resulting from severe mental illness using a psychosocial rehabilitation approach to recovery.[31] PDRSS employ community-based psychosocial rehabilitation approaches to enable consumers to 'survive, thrive and build on their strengths' as members within their communities. Such approaches 'emphasise the wholeness and wellness of the individual' (i.e. are strengths-based) and make use of a range of services to develop skills, build confidence, reconnect, and increase opportunities in life. PDRSS recognise that recovery is a complex and lengthy process, and acknowledge the total life impacts of severe mental illness rather than only the illness (symptoms) per se.

The link between social inclusion and mental health and wellbeing in a general sense is well documented. According to VicHealth:[32]

- Social networks (defined as ties, connectedness, integration, activity and embeddedness) provide emotional support, companionship and opportunities for engagement in many areas of life. By providing connections and links, social networks also act as a buffer during times of stress.

[30] For this discussion, see Crosse C and Hocking B (2004) *Social Rehabilitation: What are the Issues?* Paper for the DVA National Rehabilitation Conference, Melbourne: SANE Australia. See also Merton and Bateman, op. cit., pp. 5-6.
[31] Clark D (2003) *The Development of Psychiatric Disability Rehabilitation and Support Services in Victoria*, Elsternwick, VIC: VICSERV.
[32] Victorian Health Promotion Foundation (2005) 'Social inclusion as a determinant of mental health and wellbeing', Melbourne: Victorian Health Promotion Foundation.

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- A sense of belonging to the community makes people feel cared for, loved and valued, which in turn protects wellbeing. On the flipside, exclusion is linked to unhappiness, illness and reduced life expectancy. For example, people with few social networks are more likely to have poor health and to be at risk of (or indeed experience) some level of psychological distress. There is a strong correlation between poor social networks and mortality from almost every cause of death.

- Positive supportive relationships can foster healthier behaviour patterns and protect against less risky health behaviours.

- There is better recovery after disease when opportunities for social interactions are in place.

- There is evidence that links social inclusion with recovery/relapse prevention for those with severe mental illness.

- In a recent study in New Zealand, participants cited family and friends as the most important factor in their successful recovery. By contrast, a large-scale study conducted in the UK revealed that low social supports increased the risk of onset and decreased the chance of recovery.[33]

- A recent study on recovery and place concluded that supported housing is an integral part of a community-based recovery-focused service system.[34]

- MHCC argue that employment provides the most compelling evidence of the link between social inclusion and recovery, citing studies that associate paid work with reduced psychiatric symptoms, higher functioning, improved sense of self worth, and significant improvement in social skills. MHCC add that whilst employment is not an option for everybody, the evidence still points to strong links between having a vocation in life, a sense of purpose, and recovery.[35]

- Waghorn and Lloyd similarly argue that employment is a necessary condition for truly independent community living and a platform from which people with severe mental illness can obtain the rewarding aspects of life that others take for granted. They also note the strong association between education and opportunities for greater social inclusion (e.g. social networks, employment, financial security, and housing stability).[36]

The cost benefits

There is compelling evidence for the cost benefits of increasing community-based supports that address the 'whole of life' needs of consumers and thereby foster greater inclusivity.[37] Currently, the cost of treatment is extremely high, with bed-based hospital care the main driver/contributor. Carr et al., in their study of the costs of psychosis, conclude that a

[33] See Merton and Bateman, op. cit., p. 9.
[34] Chesters J, Fletcher M and Jones R (2005) 'Mental illness recovery and place' in *Australian e-Journal for the Advancement of Mental Health*, 4:2. See *Housing and Support – A Platform for Recovery. Background Paper* for more on housing.
[35] Merton and Bateman, op. cit., p. 26. See *Economic Participation: Employment and Education – Changing Outcomes. Background Paper* for more on employment and education.
[36] Waghorn G and Lloyd C (2005) *The Employment of People with Mental Illness*, Discussion Document, Marleston SA: Mental Health Fellowship of Australia. See *Economic Participation: Employment and Education – Changing Outcomes. Background Paper* for more on employment and education.
[37] The term, 'whole of life' is borrowed from MHCC. See Merton and Bateman, op. cit.

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disproportionate amount of money is spent on people being 'housed' (often repeatedly) in hospital (and prison); and that considerable savings could be made if we invested in evidence-based interventions to address core exclusions such as unemployment and unmet needs for stable housing. For example:

- Increased participation in meaningful vocational activities by just 10.0% of unemployed people with psychosis could potentially save society around $147 million per annum. If the rate of participation was to increase by 30.0%, the savings would be in the order of $441 million per annum. There are net cost benefits even if the investment in rehabilitation programs required to improve participation rates is taken into account—particularly for a 30.0% improvement.[38]

- The estimated average recurrent cost of providing one mental health hospital bed is around $150,000 per year (2002-2003 figure) compared to one unit of public housing at $5,990 per year (2006-2007 figure).[39]

Looking after carers

Carers of people with serious mental illness also experience poor outcomes. Carers (most often partners or mothers) play a critical role in community-based care. A recent study shows that carers, on average, contribute over 100 hours per week caring for a person with a mental illness.[40] Caring at such a level can place considerable strain on carers who typically overlook their own needs. Carers are themselves at risk of physical and mental health problems, often experiencing feelings of isolation, anxiety, guilt, helplessness, and sometimes fear for their own safety.[41]

Looking after carers can be done in community-based settings.[42] Respite provides carers with the time, space, and peace of mind to ensure their health and wellbeing. Information, education, training, peer support, and linkages to services also make a positive difference.

A comprehensive, integrated and accessible network of supports for carers ultimately means better outcomes, not only for themselves but also for those they care for.

What do we need to build social inclusion?

There is a strong body of experience and evidence that indicates a proactive combination of strategies will address barriers and promote social inclusion. The necessary strategies include:

- Partnerships between different levels of government (federal, state/territory and local) and across different departments (e.g. mental health, health, justice, housing, employment and education).

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[38] See *Economic Participation: Employment and Education – Changing Outcomes. Background Paper* for details.
[39] See *Housing and Support – A Platform for Recovery. Background Paper* for details.
[40] ARAFMI NSW (2005), *Carer Services Mapping Project*, Report for NSW Government Department of Health, as cited in Merton and Bateman, op. cit., p. 14.
[41] Merton and Bateman, op. cit., p. 14.
[42] Ibid.

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- Investment in evidence-based community supports for early intervention, recovery, and relapse prevention in order to rebalance the current (over) emphasis on a crisis-driven acute-based mental health service system.

- Integrated service delivery and improved multidisciplinary care.

- Engagement of consumers, carers and families in developing policies related to treatment and care.

- Recognition of and investment in evidence-based peer support models that support the journey of recovery.

- Better understanding and recognition of the roles of carers (including adult family members, children, and others) and investment in supports that meet their specific and changing needs.

- Responsiveness to the unique needs of individuals along multiple and intersecting axes of differences e.g. gender, age, ethnicity, language, culture, indigeneity, age of onset, stage and type of illness etc.—that is a comprehensive understanding of, and approach to, diversity.

- Development of a social inclusion and mental health research agenda.

- Investment in evidence-based community awareness raising and education initiatives, demonstrating the links between social inclusion and recovery/relapse prevention.

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Health Inequalities: policy and practice failure
Background paper

Introduction

People living with severe mental illness have an overall health status that is far lower than that of the mainstream population, resulting in significant health inequalities. However, their poorer health status cannot be explained solely by their mental illness. There is evidence to show that people with severe mental illness are also at increased risk for a range of chronic physical health conditions such as cardiovascular diseases, diabetes mellitus, respiratory diseases, obesity, and infections.[43] Having any (or several) of these physical health conditions adds further complexity to their lives; and the compounding effects of physical health and mental health issues demands effective responses from governments and health services alike.

This paper explores the health status of people living with severe mental illness through three indicators: their mortality rate, morbidity experience, and high-risk health behaviours. The paper also discusses the barriers to accessing services for good health, with particular focus on 'traditional' health services—primary, specialist and acute care. The main barrier identified is a fragmented and disjointed health service system that commonly neglects the physical health needs of people living with severe mental illness until a medical emergency occurs, or it is too late.

Before exploring these issues, it is important to briefly contextualise health inequalities within a social model of health framework given the degree to which socio-economic factors contribute to overall health status. According to VicHealth, health inequalities are the result of two key factors.[44] The first relates to barriers to resources necessary to achieve and maintain good health. Critical resources identified are: secure housing, stable employment, adequate income, education, and social inclusion. A person may experience barriers to one or more of these resources for a range of reasons, and not having access to these resources results in marginalisation, socio-economic disadvantage and poorer health. The second factor relates to barriers to accessing services that support health—not only 'traditional' health services but services in the broad 'social model of health' context e.g. transport and community-based supports. A person may experience barriers to services because of cost, inaccessibility, inappropriateness, unawareness, discrimination, or a combination of these issues. Services may exist; but not being able to use them means unmet needs and poorer outcomes.

The lack of critical resources for health amongst people living with severe mental illness is well documented in the literature and is not the focus of this paper. Some key statistics are, however, worth mentioning. These figures are drawn from the findings of a census of 3,800 Australians aged 18 to 64 with psychotic disorders undertaken by the Low Prevalence Study Group of the *National Survey of Mental Health and Wellbeing*.[45] The research method included interviews

[43] See for example Lawrence D, Holman CDJ and Jablensky A (2001) *Duty to Care: Preventable Physical Illness in People with Mental Illness*, Perth: University of Western Australia. This report is discussed further below.
[44] Victorian Health Promotion Foundation (2008) 'Burden of disease due to health inequalities' and 'Key influences on health inequalities', Melbourne: Victorian Health Promotion Foundation.
[45] Jablensky A, McGrath J, Herrman H, Castle D, Gureje O, Morgan V and Korten A (1999) *People Living with Psychotic Illness: An Australian Study 1997-98*, National Survey of Mental Health and Wellbeing Report 4, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing. This study was part of the first National Survey of Mental Health

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with 980 participants using a specifically designed instrument covering a range of socio-demographic details including occupation, income, education, housing and relationships.

The study found that 72.0% of respondents were unable to describe a regular occupation (broadly defined to include paid work as well as study, home duties, parenting and other vocational roles) and 85.2% were reliant on a government pension or social benefit (in particular the disability pension) as their main source of income. Almost half (47.8%) had not completed their schooling or gained any post-school qualifications; and whilst many lived in relatively stable forms of housing (e.g. public/private rental properties, family homes, their own homes, or supported housing) a concerning proportion (42.0%) were housed in tenuous accommodation types (e.g. institutional settings, hostels, boarding houses, rented rooms, crisis accommodation, shelters) or were homeless. Almost one-third (31.3%) lived alone and only 9.3% had a person at home they could describe as a carer.

More information on the lack of critical resources amongst people with severe mental illness can be found in the companion papers: 'Housing and Support', 'Economic Participation: employment and education' and 'Social Inclusion'.

Mental illness and chronic disease: the policy context

The extent of physical illness experienced by people with severe mental illness is even more concerning when set against the backdrop of contemporary public health discourse and the focus on preventing major chronic diseases at the population level—or at least intervening as early as possible. Included here are key policy directions and initiatives such as:

- The *National Chronic Disease Strategy*. This strategy was endorsed at the Australian Health Ministers' Conference in 2005 and provides a framework for all jurisdictions to improve chronic disease prevention and treatment through a population-based approach to health inequalities and an emphasis on integrated and multidisciplinary care planning. The self-management of chronic disease also gained prominence through this strategy, and is named as one of four key action areas along a continuum from prevention to care. The *Sharing Health Care Initiative* currently invests in a range of self-management of chronic disease education interventions.[46]

- The new *National Preventative Health Care Strategy.* This strategy will provide a 'blueprint' for further tackling the burden of chronic disease through an explicit focus on early intervention in the primary care setting (rather than later intervention in the acute setting). The recently announced *National Primary Health Care Strategy* is part of this 'blueprint' and

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and Wellbeing. The second National Survey of Mental Health and Wellbeing was conducted in 2007 with preliminary results available in late 2008.

[46] Evidence suggests that consumers with effective self-management skills make better use of health care professionals' time and acquire enhanced self care. Further study, however, is required to validate the use of self-management tools for specific groups such as people living with severe mental illness. The *Sharing Health Care Initiative* currently offers grants to fund research aimed at expanding the range of evidence-based self-management of chronic disease interventions. Hard-to-reach groups such as Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse populations, and people experiencing socio-economic disadvantage are particularly identified as the focus for research.

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includes a review of Medicare Benefits Schedule (MBS) items to better support general practitioners in the prevention and management of chronic conditions.

Also central to the *National Primary Health Care Strategy* is the development of GP-centred primary care models (e.g. GP 'super clinics') for communities with high unmet needs for services and/or high levels of (or risks for) chronic diseases.

- The recently-established National Health and Hospitals Reform Commission (NHHRC). This Commission will provide expert advice on performance benchmarks and practical reforms to meet current and future health challenges (e.g. the growing burden of chronic diseases). The Commission reports to the Federal Health Minister (and through her to the Prime Minister), the Council of Australian Governments (COAG) and the Australian Health Ministers Conference; and has been directed by Cabinet to develop a long-term national health reform plan (interim by the end of 2008 and final by mid 2009). A central part of the reform includes revising the Australian Health Care Agreements to accommodate funding focus beyond acute care to include prevention.

- The Victorian *Care in Your Community* initiative. This initiative has long recognised the impacts of a handful of chronic disease causes on the total burden of disease, including conditions that are either preventable or capable of being managed in community-based rather than bed-based hospital care. The *Chronic Disease Management Program Guidelines for Primary Care Partnerships and Community Health Services* underscore the importance of self-management in integrated chronic disease management framework.

Mental illness is often included in the group of chronic diseases targeted by these interventions, along with cardiovascular diseases, cancers, injuries, diabetes and asthma. But there is very little focus on people with mental illness—in particular, severe mental illness—as a distinct population group at high risk for a range of other chronic (physical) health conditions. It is as if people with mental illness need only to deal with their mental illness and nothing else. This suggests that despite all of this swimming 'upstream' by decision makers to prevent chronic diseases or intervene as early as possible, the development of specific responses that can effectively address the physical health problems (and poor health status) of people living with severe mental illness is yet to be seen.

Health status of people with severe mental illness

Mortality rate

The mortality rate of people with mental illness (both low and high prevalence) was revealed in a major population-based record linkage study in Western Australia.[47] The study reviewed the physical health experiences of over 240,000 people registered on the Mental Health Information System for a period of almost two decades. The study found that the death rate of people with a mental illness is considerably higher than the population in general. Overall, the death rate of

[47] Lawrence et. al. op. cit. p. xi.

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people with mental illness is 2.5 times greater than that of the general population, which is equivalent to a life expectancy of 50 - 59.

The study found a higher rate of death across each of the main physical causes, with heart disease causing the highest number of 'excess' deaths.[48] Indeed, the death rate from heart disease has not declined for this group in recent years, in stark contrast to the general population where health promotion and early intervention efforts seem to have made a difference. The rate of death through heart disease has actually increased substantially in the case of women with mental illness.

The study also found that the number of deaths in people with a mental illness, due to main physical causes, far exceeds the number of hospital admissions for related conditions. This suggests that conditions such as heart disease are not being picked up or treated until it is too late, and raises serious questions about the adequacy of the level of care received by this group. Cancer is another example: whilst incidence rates appear to be no different for people with mental illness and the general population, people with mental illness are 30.0% more likely to die from a cancer diagnosis (later detection means poorer prognosis).

Studies show that people with schizophrenia have a mortality rate that is up to three times higher than that of the general population.[49] Whilst a high number of deaths in this group can be attributed to suicide, an excess mortality is nonetheless associated with a range of physical health conditions. A Victorian study has established that patients with schizophrenia are 2.9 times more likely to die of causes such as cardiovascular disease than people in the general population.[50] According to the WA linkage study, people with affective psychoses have an excess morality associated with pneumonia, influenza and chronic obstructive pulmonary disorder. The study also shows that people with other psychoses, experience consistently elevated mortality rates across all main physical causes.[51]

Morbidity experience

Living with a severe mental illness already carries significant morbidities. However, these are often amplified through the coexistence of morbidities associated with physical health issues. Detection of chronic conditions and early intervention (not to mention prevention) remain problematic for people with mental illness who generally receive far too little attention from health service providers for their physical health needs. When considered alongside the excess mortality figures, the picture that emerges is of a group of people with complex health needs experiencing a range of morbidities for longer than necessary before being addressed (if ever) and often dying earlier as a result.

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[48] 'Excess' deaths are the number of deaths above what can be expected in the general population.

[49] Lubman D and Sundram S (2003) 'Substance misuse in patients with schizophrenia: A primary care guide' in *MJA Supplement*, 178, 71-5.

[50] Ruschena D, Mullen PE and Burgess P (1998) 'Sudden death in psychiatric patients' in *British Journal of Psychiatry*, 172, 331-6 as cited in Lambert JR, Velakoulis D and Pantelis C (2003) 'Medical comorbidity in schizophrenia' in *MJA Supplement*, 178, 67-70.

[51] Lawrence et al., op. cit., p. 36.

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Scanning the literature, Lambert et al. provide a list of physical conditions found in patients with severe mental illness.[52] These include diabetes, hyperlipidaemia, cardiovascular and respiratory disorders, obesity, malignant neoplasms, HIV/AIDS, Hepatitis C, hyperprolactinaemia, osteoporosis and irritable bowel syndrome. Some conditions are related to the side effects of medications; others derive from health behaviours that carry high risks for poor outcomes (see further below). The connections between physical health conditions and their contributing factors appear to be well documented in the literature, and practitioner awareness and response to consumer needs should be high. But they are not.

The authors of the WA linkage study similarly provide a list of physical health conditions associated with low-prevalence disorders. Added to the list by Lambert et al. are Parkinson's disease, accidental poisonings (related to prescribed and illicit substance use) and injuries inflicted on the person (whether in response to violent behaviour or victimisation). There is evidence of poor nutrition through inadequate diet as well.[53]

Lambert et al. note further that people with severe mental illness often experience elevated rates of comorbidities due to high-risk health behaviours interacting with mental illness and vice versa. Cigarette smoking, for example, is not only a risk factor for cardiovascular and respiratory conditions. By reducing available plasma levels of anti-psychotics, smoking may also influence a patient's behaviour and treatment outcomes. The cognitive and behavioural deficit symptoms of schizophrenia, compounded by the effects of certain drugs, may orient patients towards selecting certain foods that are high in fats and low in fibre (e.g. 'fast foods'), in turn, leaving them even more de-energised and unable to address their obesity or poor nutrition.[54]

Problematic substance use is common in people with schizophrenia and many have a dual diagnosis of mental illness and alcohol/other drug related disorders.[55] In Victoria, it is estimated that 20-50% of new clients of adult mental health services present with a coexisting substance abuse problem; and the prevalence rate is even higher for young adults.[56] According to Teeson et al., when compared to people with a single condition (that is, either a mental illness or an alcohol or other drug disorder) those experiencing dual diagnosis have higher rates of violence, suicidal behaviour, suicide, anti-social behaviour, and physical health problems such as infections.[57] Having a dual diagnosis can also increase the symptom severity of both conditions and impact adversely on treatment and recovery. Drug use and symptoms of withdrawal can either mimic or conceal some psychiatric symptoms making diagnosis and treatment of mental illness more complex; cognitive impairments resulting from both disorders can increase the difficulty of identification and management of a dual diagnosis.[58]

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[52] Lambert et al. op. cit., p. 67.
[53] Lawrence et al. op. cit., p. 65, p. 93 and p. 95.
[54] Lambert et al. op. cit., p. 68.
[55] Lawrence et al. op. cit., p. 95.
[56] State Government of Victoria (2008) *Because Mental Health Matters: A New Focus for Mental Health and Wellbeing in Victoria*, Consultation Paper, Melbourne: Victorian Government Department of Human Services, p. 32.
[57] Teeson M and Proudfoot H (eds) (2003) *Comorbid Mental Disorders and Substance Use Disorders: Epidemiology, Prevention and Treatment*, Report for the National Drug Strategy, Canberra: Commonwealth Department of Health and Ageing as cited in State Government of Victoria (2007) *Dual Diagnosis: Key Directions and Priorities for Service Development*, Melbourne: Victorian Government Department of Human Services, p. 5.
[58] State Government of Victoria (2007) op. cit., p. 7.

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People living with severe mental illness experience persisting poor levels of oral health e.g. poor gingival health and decaying teeth. Poor oral health adds to the overall morbidity experience of this group and is associated with a range of factors including side effects of certain medications, neglect of personal oral care, poor diet (see further below) and irregular use of dental services until emergency care is required.[59] According to one community health service in inner Melbourne, it is common to find people with severe mental illness missing several or all of their teeth, and gum disease is more pronounced in this population.[60] It is noted that full extraction was often performed on inpatients in the days of institutionalisation as a protective measure against biting carers. Another community health service offering dental services to Health Care Card holders in Melbourne's western suburbs reports that on average it provides 23.0% more treatment services to their mental health clients than all other clients, with this group requiring 10.0% more restorations and 36.0% more extractions than everyone else.[61]

Health behaviours

There is ample evidence in the literature that living with severe mental illness is associated with a range of health behaviours that carry high health risks. These include smoking, alcohol and other drug use, obesity and poor diet, underactivity and lack of exercise: all contributing factors to the morbidity experience and mortality rate.

As noted in the WA linkage study, smoking—a major risk factor for cardiovascular and respiratory conditions and lung cancer—is a common activity of people living with severe mental illness.[62] The research by the Low Prevalence Study Group found that 73.2% of male patients with psychotic disorders and 56.3% of female patients were current smokers. Moreover, of those who smoke, over one quarter (27.6%) reported a daily consumption of 30 or more cigarettes.[63] It is further noted that whilst the high smoking rates can be explained by a range of reasons (including self-medication), cigarettes are expensive and place a high financial burden on this group. Those who smoke are often least able to afford it; but smoking cessation devices, such as nicotine patches, are even less affordable.[64]

Alcohol and illicit drug use is common amongst people living with severe mental illness. In the Low Prevalence Study Group research, 11.5% of respondents described themselves as lifetime abstinent. Of those who had ever used alcohol, more than one-third (37.7%) reported drinking either daily or on several days a week in the 12 months prior to the interviews. A lifetime diagnosis of alcohol abuse or dependency was made in 30.0% of the sample. Meanwhile, 48.5% of respondents reported illicit drug use on one or more occasions. The most frequently used substance by far was cannabis. Amphetamines, LSD, heroin and tranquillisers were also reported by respondents, with the use of cocaine, phencyclidine and inhalants/ solvents less prevalent. Poly drug use was, however, a recurring theme in 19.1% of respondents. A lifetime

[59] North Richmond Community Health Centre, Oral Health Program, 'Mental illness and oral health' available at http://www.nrchc.com.au/oralhealth/ and accessed 04/07/08.
[60] Burchell A, Fernbacher S, Lewis R and Neil A (2006) '"Dental as anything" Inner South Community Health Service dental outreach to people with a mental illness' in *Australian Journal of Primary Health*, 12:2, pp. 75-82.
[61] Correspondence with the CEO at the Western Regional Health Centre.
[62] Lawrence et al. op. cit., p. 7.
[63] Jablensky et al. op. cit., p. 41.
[64] Access Economics (2007) *Smoking and Mental Illness: Costs*, Report for SANE Australia, Canberra: Access Economics, p. iv.

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diagnosis of cannabis abuse was made in 25.1% of the sample, and a lifetime diagnosis of other substance abuse/dependence was made in 13.2%.[65]

There are several reasons identified in the literature for substance use amongst this group.[66] These include social-environmental factors, e.g. socio-economic deprivations that place people with severe mental illness in close proximity to others using alcohol and illicit drugs. There may also be a biological disposition to substance use. There are self-medication reasons behind substance use as well, (adverse states induced by either the mental illness or its treatment can be mediated by psychoactive substances).

People living with severe mental illness have high rates of obesity and poor diet, e.g. consumption of foods that are high in saturated fats and low in fibre.[67] The WA linkage study provides evidence of weight gain as a side effect of certain medications; however, it is highly likely that the experience of obesity and poor diet is associated with lower socio-economic status, inadequate living conditions, and food insecurity experienced by this group.

Barriers to Accessing Health Services

Disjointed service system

Despite the excess mortality caused by physical illness and the morbidity experience arising from a range of physical health issues and high-risk behaviours, it is all too common for the physical health needs of people with severe mental illness to go unmet by health professionals. At the core of this problem is a disjointed service system. There is poor intersectoral collaboration, knowledge transfer and resource sharing between the mental health service sector and other health services such as primary care. The location of clinical mental health services in the acute/sub-acute setting further distances sections of the mental health sector from the rest of the service system. There is also a 'silos within silos' effect, with different parts of the mental health system disjointed from each other. Lack of continuity of care *within* the mental health system and *between* mental health and health services combine to create fragmented service delivery—not to mention frustration, dissatisfaction and ultimately poor outcomes for service users. As noted by the Mental Health Council of Australia, consumers end up shifting between mental health services and other health services without receiving truly effective (holistic) treatment from anyone.[68]

Blinkered mental health policy

Currently in Victoria there is a significant process in place to review and reform the mental health service system. *Because Mental Health Matters* is a consultation paper that explores new directions for mental health in Victoria, building on the COAG *National Action Plan on Mental Health 2006-2011* and the report, *Improving Mental Health Outcomes in Victoria*, commissioned by the Victorian Government in 2006. The paper makes a strong case for changing a currently overburdened and crisis-driven mental health system, which has a capacity

[65] Jablensky et al. op. cit., pp. 41-42.
[66] Lawrence et al. op. cit., pp. 7-8.
[67] Lawrence et al. op. cit., p. 76.
[68] Mental Health Council of Australia, 'Access to health services by people with mental illness', available at http://www.hreoc.gov.au/disability_rights/health/mhca.doc and accessed 04/07/08.

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to provide care only to those in most urgent need of it. As noted in the paper, many consumers have experienced severe symptoms of mental illness by the time community-based clinical care is provided—often in an acute inpatient service via the police, ambulance, a crisis team and/or a hospital emergency department. The paper goes on to state that this situation:

> *Can be compared to not treating a person with cardiovascular disease until they are experiencing a heart attack. Such a response is now generally regarded as unacceptable in respect to a physical health problem, and the same should apply to mental health treatment and care.*[69]

What the paper fails to acknowledge is that mental health consumers are not being treated for cardiovascular disease, as well as a range of other chronic physical conditions, until it is too late, and that this is unacceptable. Whilst the paper does mention the increasing 'complexity of client needs' in those with comorbid substance misuse and/or physical health problems, there is little mention anywhere—not even in the named focus area of partnerships—of a new direction towards an integrated and comprehensive mental health and health service response to meet such need (the exception being in the case of Indigenous people with mental health and physical health issues).

Practitioner factors

A disjointed service system creates a huge divide between practitioners. On one side are mental health specialists, e.g. clinical workers and, to some extent, PDRS workers, who typically overlook the physical health issues of their patients. The WA linkage study cites a number of studies showing why this happens.[70] Some specialists may regard physical complaints as psychosomatic symptoms (referred to as 'diagnostic overshadowing') or may be focused solely on the presenting psychiatric problems. Others may regard smoking and other substance use as self-medicating and so do nothing to address the physical health consequences associated with these high-risk behaviours (and even tacitly encourage it). Still, others feel they lack competence in undertaking physical examinations, or that, as specialists, they shouldn't have to deal with primary care issues, or that that their patients are too troublesome for physical examinations to be done. There are also time and resource limitations to conducting physical examinations in the mental health services setting.[71]

On the other side are primary care providers who are also reluctant to treat people with severe mental illness for their physical health issues, this time due to lack of knowledge, misconception, fear and stigma related to mental illness. There are some practitioners who dislike psychiatric patients and feel they are disruptive in the primary care setting.[72] According to Lubman and Sundram, dual diagnosis clients seem to evoke particularly powerful unpleasant feelings in health professionals who can be overwhelmed by the complexity of presenting problems and unclear about which issue to tackle first.[73] Other practitioners feel they lack adequate training in mental health issues to provide an appropriate service to this client group.[74] Still, others believe

[69] State Government of Victoria (2008) op. cit., p. 77.
[70] Lawrence et al. op. cit., pp. 8-10.
[71] Lambert et al. op. cit., p. 69.
[72] Lawrence et al. op. cit., p. 9.
[73] Lubman and Sundram, op. cit., p. 72.
[74] Lawrence et al. op. cit., p. 9.

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that too much extra effort is required to obtain a full medical history and informed consent, or that patient compliance to treatment courses will be too difficult to achieve, and so leave physical health needs unaddressed.[75] There are also significant time and resource limitations within current funding models to providing quality primary care services to this group, and often the real costs of delivering services need to be borne elsewhere (e.g. by the provider). This can act as a major disincentive on the part of providers to undertake consultations for people with severe mental illness.[76]

Whatever side of the equation, the results are the same. People living with severe mental illness 'fall between the cracks' of two service systems leaving a range of physical conditions ignored and untreated.[77] The most distressing part about this is that many of the conditions contributing to the morbidity experience and excess mortality of this group are avoidable through prevention or early intervention strategies; and that such strategies are actively promoted and applied to the general population. People with severe mental illness are therefore being denied the same level of health care provision enjoyed by the rest of the community in what effectively amounts to discrimination.

Patient factors

There are some barriers to accessing health services that lie on the side of the patient.[78] There may be a higher threshold to pain due to the effects of certain medications leaving consumers unaware of physical health issues. There may be an inability to describe/communicate problems, wait for/keep appointments, and follow treatment instructions due to cognitive and behavioural deficit symptoms. Consumers of mental health services may not be linked into the primary care system or may actively avoid contact with general health care services due to lived realities of stigma and fear of discrimination. Some patients may feel too overwhelmed by the thought of carrying out the changes required to improve their physical health.

The cost of accessing health care is a significant barrier and low-income consumers are limited to the ever-diminishing pool of providers who bulk bill. Allied health practitioners not covered by MBS subsidies can limit access to options for physical health issues. There are associated costs with getting to appointments as well.[79]

What is good practice?

This discussion has demonstrated that there is an urgent need to bring together mental heath care and physical health care into an integrated and multidisciplinary approach for people living with severe mental illness. This will not only make their experience of health care better; it will reduce existing health inequalities by attending to physical health needs earlier and more effectively. Indeed, there is a need to see specific chronic disease prevention and early

[75] Lambert et al. op. cit., p. 69.
[76] Consultation with VICSERV Reference Group.
[77] Lambert et al. op. cit., p. 69.
[78] Ibid.
[79] Mental Health Council of Australia, 'Access to health services by people with mental illness', available at http://www.hreoc.gov.au/disability_rights/health/mhca.doc and accessed 04/07/08.

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intervention strategies developed and implemented for this group. Such strategies would need to be accompanied by assertive outreach and proactive health care in all parts of the service system to ensure that people living with severe mental illness receive attention to their physical health needs. A dearth of good practice models exists; however, Lambert et al. suggest the following elements as helpful for improving service provision:[80]

- Routine use of a standard checklist and collection of core information concerning physical health amongst *all* health professionals.

- Adequate resourcing of psychiatric services to carry out physical health tasks.

- Refresher training for psychiatrists (and key members of multidisciplinary community psychiatric teams) that includes elements of detection, management and prevention of physical health conditions.

- Specific multidisciplinary teams with broad medical and psychiatric expertise and training as the basis for enhanced models of shared care.

- Formalised programs to address training and other issues at regional or state levels.

Internationally, elements of good practice can also potentially be drawn from the UK Department of Heath's *Choosing Health: Supporting the Physical Health Needs of People with Severe Mental Illness Commissioning Framework*.[81] These practice guidelines are part of the national mental health policy agenda, which focuses on the core themes of integration, recovery and social inclusion. The framework includes many examples of programs established to support people living with mental illness attain and maintain positive physical health outcomes, such as:

- Employing physical health staff in inpatient wards and developing in-reach services.

- Investment in linkages between primary and sub-acute/acute care e.g. the development of dedicated 'physical health link' workers.

- Improvement in referrals and other aspects of service coordination.

- Specific programs that deliver individual or group interventions such as smoking cessation for people with schizophrenia, walking groups, Yoga and Pilates sessions, health and wellbeing days.

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[80] Lambert et al. op. cit., p. 69.

[81] UK Government (2006) *Choosing Health: Supporting the Physical Health Needs of People with Severe Mental Illness*, Commissioning Framework, London: Department of Health.

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Economic Participation: employment and education – changing outcomes - *Background paper*

The benefits of employment

The benefits of employment for people living with severe mental illness are well documented. In their report on employment and psychosis for the *National Survey of Mental Health and Wellbeing*, Frost et al. argue that aside from providing opportunities to contribute economically and socially to the community, employment can also assist in the journey of recovery.[82] Citing numerous studies, the authors write that employment has been found to diminish symptoms, reduce hospitalisations, increase independence (not just financially), improve self-worth, and enhance social skills. The authors conclude that:

> *Employment is not only a necessary condition for truly independent community living but also a platform from which people with chronic mental illness can obtain the rewarding aspects of mainstream living that most people take for granted.*[83]

Waghorn and Lloyd similarly refer to a number of studies that identify the benefits of employment for people living with severe mental illness.[84] Employment is linked to improved self-concept and self-efficacy, higher rates of self-reported wellbeing, a regaining of self-esteem and personal empowerment, and reduced clinical symptoms. Employment gives people with severe mental illness structured time and routine, opportunities for social contact and participation, a sense of collective effort and shared purpose, increased social identity and status, and a feeling of personal achievement. In addition, the benefits of employment flow beyond the individual to the wider community. Personal contact with those experiencing severe mental illness in the workplace can do much to counter the myths and stigma associated with mental illness in mainstream society and raise awareness of the issues, difficulties and disadvantages experienced by those living with low prevalence disorders.

One other way to consider the benefits of employment is to look at the negative impacts of unemployment. According to Bill et al., unemployment has negative consequences for anyone in terms of self-confidence, competence, integration, responsibility and freedom.[85] It leads to financial precariousness, poor quality of life, poverty and isolation. It is, in short, a form of marginalisation and exclusion. But unemployment does not affect the community evenly. Amongst those hardest hit are people living with severe mental illness, further compounding a range of unmet needs due to socio-economic disadvantage.

At a broader level, unemployment has been found to contribute significantly to the total cost impact of psychosis on the community. In their study on the costs of psychosis, Carr et al. found a strong association between employment and a reduced cost burden borne by society,

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[82] Frost B, Carr V and Halpin S (2002) *Employment and Psychosis*, National Survey of Mental Health and Wellbeing Bulletin 3, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing, pp. 1-2.
[83] Ibid., p. 5.
[84] Waghorn G and Lloyd C (2005) *The Employment of People with Mental Illness*, Discussion Document, Marleston SA: Mental Health Fellowship of Australia, pp. 14-15.
[85] Bill A, Cowling S, Mitchell W and Quirk V (2004), *Creating Effective Employment Solutions for People with Psychiatric Disability*, Working Paper No. 04-06, Centre of Full Employment and Equity, Callaghan: University of Newcastle, pp. 10-11.

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including government.[86] People with psychosis who are engaged in meaningful activities (such as employment, study or other vocational roles) incur less expense for their condition than non-participants. In other words, there may be real cost benefits to the community in increasing rates of participation in meaningful employment (commensurate with abilities and interests) for those with psychotic disorders. Indeed, Carr et al. estimate that increased participation in meaningful activities by just 10% of unemployed people with psychosis could potentially save society around $147 million per annum in costs. If the rate of participation increased by 30%, the savings would be around $441 million per annum. There are net cost benefits even if the investment in rehabilitation programs required to improve participation rates is taken into account—particularly for a 30% improvement.[87] Along with the benefits that employment brings at the individual level, it makes economic sense to the community as well.

Demographic trends provide another compelling economic argument for the employment of people with severe mental illness. According to the Australian Chamber of Commerce and Industry, current fertility and migration rates will not offset the impact of a shrinking workforce as 'baby boomers', retiring in the next decade or two. The workforce currently grows by about 180,000 people per year; but in just 12 years time, and for the decade 2020 to 2030, that figure will fall dramatically to 18,000 per year. Productivity, gross domestic product, and standards of living, are all likely to be affected by this trend unless policies are put in place now.[88] People with severe mental illness currently represent an under-utilised and untapped segment of the labour market and could potentially become part of a national workforce strategy for our ageing population.

Workforce non-participation and unemployment

Despite widespread agreement on the benefits of employment and (conversely) the harmful consequences of unemployment, there is still much to be done to give people living with severe mental illness real opportunities to achieve and maintain paid work. The reality is that for many in this group, the prospects of secure employment are a distant proposition. Chronic unemployment resulting in increased welfare dependency, poverty, socio-economic disadvantage, and associated unmet needs are the abiding features in their lives.

The workforce non-participation rate of people living with severe mental illness was captured through a census of 3,800 Australians aged 18-64 with psychotic disorders undertaken by the Low Prevalence Study Group of the *National Survey of Mental Health and Wellbeing*.[89] The research method included interviews with 980 participants using a specifically designed instrument covering socio-demographic details such as participation in paid work. The research found that 72% of participants could not describe a regular occupation (whether paid work, study or unpaid work) at the time of the interviews; and that this was the case for 58.3% of

[86] Carr V, Neil A, Halpin S and Holmes S (2002) *Costs of Psychosis in Urban Australia*, National Survey of Mental Health and Wellbeing Bulletin 2, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing, p. 33.
[87] Ibid., p. 34.
[88] 'Baby boomers' retirement has dire consequences', *ABC News*, posted 23/07/08 7:14 a.m. AEST, available at http://www.bananasinpyjamas.com/news/stories/2008/07/23/2311523.htm and accessed 31/07/08.
[89] Jablensky A, McGrath J, Herrman H, Castle D, Gureje O, Morgan V and Korten A (1999) *People Living with Psychotic Illness: An Australian Study 1997-98*, National Survey of Mental Health and Wellbeing Report 4, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing. This study was part of the first National Survey of Mental Health and Wellbeing. The second National Survey of Mental Health and Wellbeing was conducted in 2007 with preliminary results available in late 2008.

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participants for the 12-month period leading up to the study. Indeed, in the 12-month period prior to the interviews, only 9.8% reported regular full-time work. Not surprisingly, only a small proportion (15.5%) reported financial independence through income drawn from wages or salary, with the majority (85.2%) in receipt of a government pension or social benefit (in particular the disability pension) as their main income source.[90]

Waghorn and Lloyd estimate that the rate of workforce non-participation amongst people with psychotic disorders in Australia is actually around the 75-78% mark, compared to 75-90% in the USA and 61-73% in UK.[91] According to the Mental Health Council of Australia (MHCA) this means only two in ten Australians with a psychotic disorder are currently in some form of employment.[92] The MHCA also draws on the ABS *1998 National Survey of Disability, Ageing and Carers* to show that people with psychiatric disabilities have the highest rate of workforce non-participation (71.2%) compared to other disabilities (these being intellectual, head injury/stroke/brain damage, sensory and physical).[93] More up-to-date figures released by the Australian Safety and Compensation Council (ASCC) and using a slightly different nomenclature of disability types reveal an overall workforce non-participation rate of 73.6% amongst people with disability due to mental illness, second only to the rate for people with disability due to 'nervous and emotional condition' (76.3%).[94]

According to the latest figures available through the ABS, the unemployment rate amongst those with severe mental illness has increased significantly since the *1998 National Survey of Disability, Ageing and Carers*.[95] In 1998, the unemployment rate was 7.2%; in 2003, it was 19.5%, the highest of all disability types.[96] Meanwhile, the unemployment rate for the population overall has fallen during the last ten years; at June 2008 the rate was 4.2%.[97] Consistent with the figures above, the workforce non-participation rates for people with severe mental illness have more or less stayed the same (71.8% in 2003) suggesting that of those non-participating, it is the impetus to be in paid employment that has changed between these two periods.

Whatever the figures used, the undeniable point is that there is a high rate of workforce non-participation in this group and a high rate of unemployment. Yet, the goal of realising a vocation in life—including, but not exclusive to, being in a paid job—remains a high priority for

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[90] Ibid., p. 43.
[91] Waghorn and Lloyd op. cit., p. 4.
[92] Mental Health Council of Australia (2007) *Let's Get to Work: A National Mental Health Employment Strategy for Australia*, Deakin ACT: Mental Health Council of Australia, p. 17.
[93] Ibid., p. 18.
[94] Australian Safety and Compensation Council (2007) *Are People with Disability at Risk at Work? A Review of the Evidence*, Canberra: Department of Education, Employment and Workplace Relations, p. 66.
[95] The non-participation rate includes people who have retired, are studying, or occupied in activities that encompass unpaid work (e.g. care of children). The unemployment rate, as opposed to the non-participation rate, is the rate of those in the population not participating in the workforce and actively looking for work.
[96] The figure for 1998 is from the ABS *1998 National Survey of Disability, Ageing and Carers* as cited in Mental Health Council of Australia, op. cit., p. 18. The figure for 2003 is from the Australian Bureau of Statistics (2004) *Disability, Ageing and Carers: Disability and Long Term Health Conditions, Australia 2003*, Table 17, Cat. No. 4430.0.55.002, Canberra: Australian Bureau of Statistics, available at http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.0.55.0022003?OpenDocument and accessed 08/07/08.
[97] Australian Bureau of Statistics (2008) *Labour Force Australia, June 2008*, Cat. No. 6202.0, latest issue released at 11:30 a.m. Canberra time 10/07/08, available at http://www.abs.gov.au/AUSSTATS/abs@.nsf/mf/6202.0 and accessed 31/07/08; Commonwealth of Australia (2008) *Employment Assistance for People with Mental Illness: Literature Review*, Canberra: Department of Education, Employment and Workplace Relations, p. 14.

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many with severe mental illness.[98] In the final report of their national inquiry into the human rights of people with mental illness, the Human Rights and Equal Opportunity Commission (HREOC) found discordance between the importance of paid work in people's lives and its actual achievement.[99] Waghorn and Lloyd similarly suggest that high unemployment rates in no way imply unwillingness to work or the unfeasibility of gaining employment. This is borne out in recent research, which shows that people with psychiatric disabilities represent the largest disability group accessing disability employment services (at 30.0%) despite faring the worst in employment outcomes (both securing and retaining work).[100] Other studies show that people living with severe mental illness continue to strive to find a meaningful vocational place for themselves in society, as workers, students, volunteers, consumer advocates, parents, homemakers, etc.[101] With appropriate supports, it is possible to include vocational options as part of their rehabilitation plan; and indeed, many people living with severe mental illness go on to achieve their vocational goals including employment.

As pointed out by MHCA, Australia is a signatory to the United Nations *Covenant on Economic, Social and Cultural Rights*.[102] Article six states that those party to the Covenant will recognise the rights of everyone to opportunities to gain their living through work that is freely chosen, and will take appropriate steps to safeguard these rights (including policies, training and guidance). Whilst several mental health strategies across Australian jurisdictions exist that reflect the principles contained in the Covenant (e.g. the Council of Australian Governments (COAG) *National Action Plan on Mental Health 2006-2011*) the workforce non-participation and unemployment rates experienced by people with severe mental illness suggest that rhetoric has not translated into outcomes for this group.

MHCA go on to add that what is needed is a dedicated employment strategy for people with mental illness; here echoing the findings from the 2005 final report of the HREOC *National Inquiry into Employment and Disability*.[103] The HREOC report recommended a nationally led initiative to increase workforce participation amongst those with disabilities through the development of a mental health employment strategy. Since the last federal election, and under the banner of the new social inclusion agenda, there are promising signs that something is starting to take shape. There is currently a process in place for developing a *National Mental Health and Disability Employment Strategy* and a parallel review of publicly-funded employment services.[104]

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[98] Frost et al., op. cit., p. 7.
[99] Human Rights and Equal Opportunity Commission (1993) *Report of the National Inquiry into the Human Rights of People with Mental Illness*, Canberra: Human Rights and Equal Opportunity Commission, as cited in Bill et al. op. cit., p. 10.
[100] Waghorn and Lloyd, op. cit., p. 4.
[101] Ibid., pp. 13-14.
[102] Mental Health Council of Australia, op. cit., p. 5.
[103] Ibid., p. 16. Indeed, the MHCA paper was written in the absence of a national employment strategy for people with mental illness. See also Human Rights and Equal Opportunity Commission (2005) *WORKability II: Solutions, People with Disability in the Open Workplace*, Final Report of the National Inquiry into Employment and Disability, Sydney: Human Rights and Equal Opportunity Commission.
[104] Commonwealth of Australia (2008) *National Mental Health and Disability Employment Strategy*, Discussion Paper, Canberra: Commonwealth Government Department of Education, Employment and Workplace Relations; and Commonwealth of Australia (2008) *The Future of Employment Services in Australia*, Discussion Paper, Canberra: Commonwealth Government Department of Education, Employment and Workplace Relations.

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Education as a pathway to employment

There is evidence to show that levels of educational attainment are strongly associated with rates of workforce participation amongst people with severe mental illness. According to Waghorn and Lloyd, the number of people with psychotic disorders who are employed increases proportionately with the number of secondary school completions, vocational qualifications, and degree qualifications.[105] Conversely, the high rate of workforce non-participation in this group is related to a high rate of interrupted education. The research by the Low Prevalence Study Group found that almost one half (47.8%) of participants had neither finished their secondary school education nor achieved post-secondary qualifications.[106]

Interruptions to education are due to the particular characteristics of illness onset, which typically occurs in early adulthood during a critical time of education completion and early career preparation. Again, from the Low Prevalence Study Group research, the average age of illness onset amongst participants was found to be from 24 to 25.[107]

For those who become unwell during secondary school, there is often very little by way of support to enable them to continue studying. Indeed, our education system may be unwittingly facilitating the rates of non-completion of compulsory education amongst this group. As put by one teacher:

> *Our core business is education – we identify children with intellectual disability but not psychiatric disability. We are not funded to support these kids. We can provide inclusive resources but we can't really do it properly. Generally they are just piece meal packages … I have staff using the expulsion/suspension guidelines to exclude these kids. Actually, they really need care.*[108]

Despite the low levels of educational attainment amongst people with severe mental illness, the goal of achieving an education—like employment—remains a high priority for many. For example, a Western Australian study on vocational education and training involving 26 people with a psychiatric disability found that around three-quarters of participants wanted to undertake educational activities as one of their priorities in life.[109] Yet, people with severe mental illness continue to be under-represented in vocational education and training systems, suggesting barriers to restoring educational trajectories. These barriers are discussed further below (see 'Barriers to Restoring Educational Trajectories').

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[105] Waghorn and Lloyd, op. cit., 11.
[106] Jablensky et al. op. cit., p. 32.
[107] Ibid., p. 10.
[108] Mental Health Council Australia (2005) *Not for Service: Experiences of Injustice and Despair in Mental Health Care in Australia*, Canberra: Mental Health Council Australia, p. 180.
[109] Pathways to Opportunities Program, Ruah Inreach (2004) *People Living with Mental Illness and Vocational Education and Training*, Perth: Government of WA Department of Education and Training, p. 30.

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Barriers to employment

Clearly, we could be doing much more to support people living with severe mental illness to realise their vocational aspirations, particularly with respect to employment. Understanding the barriers to workforce participation will help inform any strategies for improving outcomes. Whilst some barriers to employment are directly related to the symptom profile of low prevalence disorders and the side effects of anti-psychotic (and other) drugs, there is evidence to suggest that the most significant barriers stem from inappropriate service provision/support, broader community beliefs and misconceptions about mental illness, and the marginalised place given to those with mental illness in our 'age of reason'. These 'indirect' barriers are modifiable, albeit intransigent, and can therefore be the focus for change.

In discussing barriers to employment, it is important to keep in mind a 'life stages approach' and three broad cohorts with very different needs. The first group includes younger people whose diagnosis came at a time when a vocational direction was being established. Re-engagement with this direction would be the issue here. The second group incudes those who are older and whose diagnosis interrupted an established career. People in this group are likely to have a skills set and employment experience base to draw on during their rehabilitation, however, may need support reorienting their career in light of their mental illness. The third group includes those who are older, perhaps with a history of institutionalisation, and who have never established a vocational direction or are temporally removed from their original vocational path. The needs of this group are potentially much more complex than the other two.

Disrupted vocational trajectory

An interrupted education leads to a disrupted vocational trajectory and longer-term consequences for restoring direction, e.g. loss of confidence and difficulty in identifying vocational goals.[110] An interrupted education can also lower vocational expectations, limit career prospects, displace one 'downwards' to less-skilled jobs or into part-time jobs when full-time work is sought (underemployment), and precipitate instantaneous unemployment that has the potential to become long term.[111] These add up to significant barriers in terms of achieving meaningful employment.

Limitations through symptoms

The symptoms of severe mental illness typically manifest as impairment, functional limitation or role restriction that vary considerably across time.[112] There may be periods of good functioning that fluctuate with levels that are less than optimal. It is the course of severe mental illness that can (but not always) pose restrictions to engagement in a range of vocational activities.[113] As Harvey et al. write, 'the more protracted the episodes of illness, the shorter the periods of remission and/or the greater the "residual symptomatology", the more substantial the negative

[110] Frost et al., op. cit., p. 11.
[111] Waghorn and Lloyd, op. cit., p. 11.
[112] Ibid., pp. 8-9.
[113] It is, of course, important to note that the impacts are on an individual basis since psychosis represents a heterogeneous set of conditions and its experience is different from person to person.

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impact on social and occupational functioning.'[114] People with severe mental illness face the specific issue of finding paid work with job designs that are suitable to their skills and flexible enough to accommodate the episodic nature of their condition.

Sector isolation and system failure

Perhaps the most fundamental indirect barrier to achieving better employment outcomes for people living with severe mental illness lies in sector isolation and its correlates: poor inter-sectoral collaboration, knowledge transfer, and a system that fails those it is intended to support. For example, mental health services continue to be isolated from vocational rehabilitation services and vice versa. This means clinicians can be unaware of developments in the field of psychiatric vocational rehabilitation, and vocational specialists can be unaware of the latest clinical treatments that might address symptoms they regard as employment limitations. When uncoordinated, 'both treatment and vocational plans are at risk of mutual interference, which, at any time, can obstruct progress in both domains and negatively impact on mental health consumers, their families and carers'.[115]

Sector isolation is further compounded when Psychiatric Disability Rehabilitation and Support Services (PDRSS) are put in the frame. As noted by Frost et al., the need for rehabilitation is often overlooked by mental health clinicians in the early stages of psychosis; as time lapses, so too does what can be achieved by rehabilitation in terms of recovery and self-determination in social and economic participation.[116]

There is no doubt that effective partnerships between mental health, vocational rehabilitation, and specialist employment services would result in better employment outcomes. It is also important to remember that many consumers have complex needs around housing and health as well. (See the companion papers in this series on 'Housing and Support' and 'Health Inequalities' for more.) It is likely that those looking for work require other services alongside employment assistance. But when the majority of these services—and the sectors they belong to—operate in 'silos', there is little chance that consumers will be appropriately linked. Many miss out on services or drop out of the system entirely, meaning they don't find work, or gain appropriate housing, or have their health needs met.[117]

Navigational complexities in using employment (and other) services

This barrier is related to sector isolation and refers to the experiences of the job seeker. The main publicly-funded employment services available to people with disabilities are generalist Job Network providers funded by the Department of Education, Employment and Workplace Relations (DEEWR), and a range of non-government and private organisations specialising in disability employment services (i.e. DEN) funded by the Department of Family and Community Services. A small number of DEN providers specialise in assisting people with psychiatric

[114] Harvey C, Evert H, Herrman H, Pinzone T and Gureje O (2002) *Disability, Homelessness and Social Relationships Among People Living with Psychosis in Australia*, National Survey of Mental Health and Wellbeing Bulletin 5, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing, p. 3.
[115] Waghorn and Lloyd, op. cit., p. 5.
[116] Frost et al. op. cit., p. 15.
[117] Mental Health Council of Australia, op. cit., p. 33.

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disabilities (e.g. Groundwork (EACH), Prahran Mission, Pathways and Reachout).[118] Other options for people with disabilities are the publicly-funded vocational rehabilitation services (VRS). These services are provided by CRS Australia (funded by DEEWR) and others. The Personal Support Program (PSP) is also available to people with severe mental illness. The PSP provides intensive support to those experiencing challenging circumstances in their lives and barriers to workforce participation (e.g. homelessness, problematic substance use, mental illness, and family violence). To use any of these services, job seekers must first be 'streamed' by undertaking a 'Job Capacity Assessment' or JCA. The majority of JCAs are done through Centrelink, the publicly-funded income support agency.

Nearly all services that may be used by job seekers with severe mental illness are federally funded. Whilst few (if any) employment and income support services are funded by state/territory governments, this is not the case for mental health services and PDRSS. These are almost wholly funded through state/territory jurisdictions. Yet, between these two major service types—mental health and employment—are very few embedded linkages. There is instead a 'constellation' of shared federal and state government funding arrangements to administer various programs available to the consumer, not to mention split departmental responsibilities across federal/state levels. What this amounts to are significant navigational complexities for unemployed people with psychiatric disabilities. As Waghorn et al. write:

> *[A] job seeker with severe mental illness may need to access and coordinate three or more sectors across two levels of Government. For instance, a job seeker may be simultaneously engaged with a State or Territory mental health service, the Federal income support agency, and a private disability employment service contracted to the Federal government.*[119]

If housing and health needs are thrown into the mix, the consumer experience becomes even more complicating, confusing and frustrating. Waghorn and Lloyd note that unless someone steps up to coordinate everything, the task is left to the person least able to perform this role: namely, the consumer. They add that 'inadvertent exclusion' to employment is the most likely outcome of these navigational complexities.

Factors related to job capacity assessment

The JCA can paradoxically act as a barrier to positive employment outcomes. As mentioned, job seekers with psychiatric disabilities must undertake a JCA by Centrelink to determine eligibility into publicly-funded employment service streams. On one hand, assessors can underestimate the assistance needs of job seekers during times of relative symptom stability. As Frost et al. note, the assessment is not sensitive to a course pattern of illness approach but rather takes a 'cross-sectional' view of the presenting client.[120] On the other hand, assessors can overlook the real difficulties experienced by some clients in undertaking the actual assessment. Either scenario has implications for the level of support received and the eventual employment outcomes for the client. Clients can find themselves in receipt of support that does not match needs, putting

[118] Ilsley B (2007) 'Employment of people with a mental illness: Issues and implications for the Psychiatric Disability Rehabilitation and Support Services sector' in *New Paradigm*, June, p. 18.
[119] Waghorn G, Collister L, Killackey E and Sherring J (2007), 'Challenges to implementing evidence-based supported employment in Australia', in *Journal of Vocational Rehabilitation*, 27, p. 31.
[120] Frost et al., op. cit., p. 6.

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them in constant danger of infringing job search requirements (and having to carry associated financial penalties). Being incorrectly 'streamed' also means that a successful job seeker may not receive appropriate ongoing support to keep their employment.[121]

This skills deficiency of employment services assessors in working with people with serious mental illness is documented in the Commonwealth Ombudsman's *Annual Report 2006-2007*.[122] The report identifies a concern that the number of people with mental illness who 'fall through the cracks' is a result of the current service model. These are people who wish to obtain employment but who find themselves inappropriately 'streamed' into employment services through the process of the JCA.

Capped programs

The current employment services system places limits on the number of clients accessing programs such as PSP, DEN and VRS. Capping produces long waiting lists and discontinuity in service provision—both of which are counterintuitive to the rapid job searching approach of early intervention. Capping can also mean unsuitable referrals to Job Network, a generalist service for job seekers who do not require specialist support for finding work. People with severe mental illness referred to Job Network can miss out on critical supports they may need. And, as mentioned previously, being placed in Job Network can expose consumers to activity requirements that are particularly challenging given the episodic nature of their condition. Even if Job Network services reveal themselves to be clearly inappropriate for clients with severe mental illness, there is no easy way to be transferred to other programs, or to access other programs, due to capped places and administrative (bureaucratic) barriers.[123]

A disincentive system

The 'Welfare to Work' changes to income support introduced in 2006 have heightened anxieties around potential loss of income supports. The changes included new measures around payment arrangements and activity regimes for identified target groups including people with disabilities. Clients can now be referred to Centrelink to undertake a JCA for their Disability Support Pension (DSP) claims, and having an assessment immediately starts a review of their entitlements. If assessors find that work capacity exceeds the hours allowed under the pension or that the client's impairment is less than a certain number of 'points', then their DPS can be cancelled. Whilst clients may be entitled to other types of payments (such as Newstart) it is the fear of losing existing payments that is paramount.[124] (Newstart provides less generous entitlements than the DPS.)

In this climate of fear, consumers are also concerned about their chances of re-establishing income and welfare supports should they need to in the future. Job seekers are sometimes reluctant to demonstrate their willingness to work for fear of losing their DSP and not being able to regain it and associated benefits (e.g. Health Care Card) should they get and then

[121] Mental Health Council of Australia, op. cit., pp, 28-9.
[122] Commonwealth Ombudsman (2007) *Annual Report 2006-2007*, Canberra: Commonwealth of Australia, as cited in Mental Health Council of Australia, op. cit., p. 28.
[123] Mental Health Council of Australia, op. cit., p. 64.
[124] Ibid., p. 28.

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subsequently lose a job through relapse.[125] In this sense, 'Welfare to Work' has functioned as a disincentive scheme.[126]

Stigma and disclosure issues

Stigma exists in the service system, the workplace and wider community and acts as a major barrier to employment outcomes for people with severe mental illness. According to Waghorn and Lloyd, mental health professionals can have low expectations of the vocational capacities of their patients, mirroring wider societal beliefs that those with psychiatric disabilities are unfit for work.[127] Frost et al. concur with this finding, citing several studies that show that very few clients are asked about their vocational interests by their mental health workers.[128] This leads to bias towards prevocational programs and reluctance to engage with vocational rehabilitation services. Within the vocational rehabilitation sector, professionals without training in the specialist field of psychiatric vocational rehabilitation may favour the selection of consumers with more familiar/stable mental illness. The end result is that those with the most severe mental illness are even more marginalised by the services that are there to help them.[129]

None of this is helped by the fact that the pool of employers available to recruit people with severe mental illness is limited due to misconceptions about mental illness. Whilst no Australian studies exist, evidence in the UK shows that a significant proportion of senior managers do not have workplace mental health policies in place. Of those who do, only 16% believe they are well understood and even less (14%) feel they are effective. This same study revealed that a significant number of employers believe that employees with mental illness are a significant risk to the organisation (e.g. loss of productivity due to periods of leave). Some believe that leave periods of more than a few weeks means that recovery is not possible, and that paying out employees rather than supporting their return to work would be a preferred option.[130]

Disclosure is a major issue for people living with severe mental illness and is felt a number of levels. At the start of the job seeking process are the employment services. Through the JCA, the weight of disclosure is placed on the individual. A person may choose not to disclose their illness to Centrelink and/or employment service providers due to fear of discrimination and the impact on employment prospects if they do. This can have a bearing on the way a job seeker is 'streamed' into employment services. Along with the limitations of the current JCA model to appropriately assess people with mental illness, the disclosure issue is another factor that contributes to clients being inappropriately matched to supports.[131]

Within the workplace, disclosure remains problematic due to fear of discrimination or embarrassment about mental illness. A recent SANE Australia survey of 284 people with mental

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[125] Ibid., p. 31.
[126] Ilsley, op. cit., p. 19. In July 2008, the Federal Government decided to protect the incomes DSP job seekers. From September 2008, the assessment of pension eligibility will be separated from the assessment of employment assistance needs and people on DSP will be able to have employment assistance needs assessed without fear of losing income in the process.
[127] Waghorn and Lloyd, op. cit., pp. 25-26.
[128] Frost et al., op. cit., p. 14.
[129] Ibid., p. 7.
[130] Future Foundation (2006) *Mental Health the Last Workplace Taboo: Independent Research into What British Business Thinks*, Wiltshire UK: Shaw Trust as cited in Mental Health Council of Australia, op. cit., p. 25 and p. 27.
[131] Mental Health Council of Australia, op. cit., pp, 28-9.

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illness found that over half (57%) of those who had ever worked had disclosed their condition to their employers. Of those who had disclosed, 67% said that it had been helpful in fostering a more understanding work environment for them and alleviating stress at work.[132]

Lack of longer-term supports for job retention

Appropriate supports are the key not only to attaining employment but retaining it as well. Many people with severe mental illness require longer-term supports to keep their job once employment has been achieved. The current employment service system does not provide for such supports. Resource and time limitations built into most existing contracts with publicly-funded providers, mean they are not in a position to develop and sustain truly effective relationships with clients to ensure successful job retention.[133]

A comparison can be made with the Structured Training and Employment Projects (STEP) for Indigenous job seekers that attempt to provide employment support over a longer span of the pre-employment, placement and post-placement phases. According to MHCA, there may be benefits in providing similar programs to people with severe mental illness, given the overall cost burden borne by the government and community through high levels of unemployment and workforce non-participation in this group.[134]

Housing insecurity

It is difficult to overlook housing insecurity as a major barrier to employment outcomes for people living with severe mental illness. The Low Prevalence Study Group research found that 42% of participants were living in tenuous forms of accommodation (e.g. institutional settings, hostels, boarding houses, rented rooms, crisis accommodation, and shelters) or were homeless at the time of the interviews.[135] Unmet accommodation needs do little to engender the sense of stability required to facilitate employment (and indeed, other vocational) directions. It is highly likely that a large number of people with a psychiatric disability, who are capable of greater economic participation, are restricted by housing insecurity brought about by marginal forms of accommodation.[136]

Barriers to restoring educational trajectories

Given the strong link between educational attainment and employment outcomes, it is important to address disrupted educational trajectories as part of an effective vocational rehabilitation approach for people living with severe mental illness. There are, however, a number of barriers that present to this group making it difficult to undertake education activities as part of their rehabilitation plan. In discussing these barriers, it is worthwhile to keep in mind a 'life stages approach' and three broad cohorts identified above: younger people who are 'close' to their original vocational path, older people whose illness interrupted established careers, and older people who have never established a vocational direction in their lives.

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132 SANE Australia (2006) *Research Bulletin: Employment and Mental Illness*, South Melbourne: SANE Australia.

133 MHCA notes that where people with severe mental illness receive employment assistance through a DEN provider the outcomes have been shown to be positive. The problem, however, is in the limited DEN places available because of capping. See Mental Health Council of Australia, op. cit., p. 56.

134 Mental Health Council of Australia, op. cit., p. 34.

135 Jablensky et al. op. cit., p. 33.

136 Frost et al. op. cit., p. 22.

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Limitations through symptoms

The symptoms of severe mental illness can impact on thinking, behaviour, perception, judgment and affect, and there may be certain side effects from medications as well. The symptom manifestations of severe mental illness present unique challenges around the actual task of studying and learning, getting to every class, navigating one's way across campus, and getting through classes without breaks. Whilst on-campus learning support services are available to students with disabilities, educational institutions often lack appropriately trained teachers and support personnel to meet the specific learning needs of people with psychiatric disabilities.[137]

Due to the characteristics of their symptoms, people with severe mental illness can also experience barriers with regard to a range of administrative processes characteristic of educational institutions. These include the sometimes complex task of enrolment and selecting subjects, the lack of recognition for prior learning, and academic records that show 'fail' rather than 'incomplete' due to relapse.[138]

Literacy and numeracy issues

For those who became unwell during their secondary school years and/or have a history of institutionalisation, there may be added literacy (including computer) and numeracy issues that act as further barriers to pursuing education options.[139]

Costs of study

Study can be expensive and people living with severe mental illness can find the cost of pursuing education activities prohibitive given their lower socio-economic status.[140] There are costs associated with fees, and whilst HECS can be deferred for people with psychiatric disabilities undertaking university level studies, the debt still has to be paid in the long run. This may seem daunting enough for some to discount education as an option. There are also a host of non-tuition related costs to consider involving transport, the purchase of computers, resources and materials, etc. Some people with psychiatric disabilities also have fears about how their enrolment might impact on their entitlements to income support.

Sector isolation and system failure

There is poor (almost non-existent) collaboration between vocational education and training providers, the mental health sector, and disability employment services to assist people with psychiatric disabilities in restoring disrupted education trajectories. Partnerships are ad hoc rather than part of an integrated system. As noted in the discussion paper for the *National Mental Health and Disability Employment Strategy*:

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137 Pathways to Opportunities Program op. cit., pp. 44-7.
138 Ibid., pp. 49-52.
139 Ibid., p. 62.
140 Ibid., op. cit., 36-41.

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In the same way that people with disability and/or mental illness are under represented in employment, so too are they under represented in vocational, education and training systems. This situation is exacerbated by poor links between state-administered school and post-school programs and Commonwealth-administered disability employment services.[141]

Stigma

People with psychiatric disabilities report being worried that their condition will be obvious to teaching staff and other students and that this will lead to negative treatment.[142] Fear of discrimination is sometimes enough to deter some from considering study as a viable option in life. For those who are older and thinking about returning to study, there may be additional reservations about being in a mainstream classroom situation with students much younger than themselves.

Housing insecurity

As with employment, unmet accommodation needs mean that people living with severe mental illness are often without a base from which to pursue education options. It is highly likely that a large number of people with a psychiatric disability, who wish to return to study as part of their rehabilitation, are restricted by housing insecurity.

Achieving employment outcomes: what works?

All people have the right to opportunities for social and economic participation, however, the significant barriers to achieving and retaining paid work amongst those with severe mental illness require evidence-based strategies to put things right—and for this to be done as early as possible in the life course of the illness.

At the heart of such interventions is an approach that integrates specialist employment services with mental health services. This approach, known as specialised supported employment, draws heavily on the model of Individual Placement and Support (IPS) developed by Robert Drake and Deborah Becker at the New Hampshire-Dartmouth Psychiatric Research Centre in 1993. IPS-based programs have been extensively evaluated and typically result in employment outcomes for 40-60% of participants—up to three times greater than programs without integration.[143]

According to Waghorn and Lloyd, in addition to the overall outcomes achieved by IPS-based programs there is strong evidence of effectiveness for most of its core principles.[144] These are:

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141 Commonwealth of Australia (2008) *National Mental Health and Disability Employment Strategy*, op. cit., p. 11.
142 For this discussion see Pathways to Opportunities Program, op. cit., p. 26 and p. 31.
143 Bond G (2004), 'Supported employment: Evidence for an evidence-based practice' in *Psychiatric Rehabilitation Journal*, 22:4, pp. 345-59. The use of the term 'specialised supported employment' is used in the IPS sense. It is not to be confused with the use of a similar term in Australia, 'supported employment', which refers to group-based sheltered work provided by business services through modified (i.e. not fully open or competitive) settings. See Waghorn and Lloyd, op. cit., p. 5.
144 Waghorn and Lloyd, pp. 30-1.

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1. Eligibility for employment services based on consumer choice, not job readiness.

2. Integration of disability employment services with mental health care.

3. The goal of competitive or open employment.

4. Rapid commencement of job searching activities.

5. Job placements based on consumer preferences, strengths, experience, and interests.

6. Continuing support to retain employment.

7. Income support and benefits counselling.

There is emerging evidence of effectiveness for the following 'ingredients' from other models such as transitional employment, vocational rehabilitation specialising in psychiatric disability, and non-specialised vocational rehabilitation. Ingredient 11 reflects an emerging candidate although there is not yet clear evidence to support this strategy for employment outcomes (but there is for mental health promotion).

8. Continuous availability of intensive onsite workplace support.

9. Multidisciplinary teams to coordinate treatment and vocational interventions.

10. Alliance between staff and consumers in rehabilitation.

11. Strategies to counter workplace stigma.

Waghorn and Lloyd argue for an 'ingredients' approach to the principles of evidence-based practice to avoid a 'model-versus-model' scenario. In Australia, ingredients that are not routinely used in the delivery of employment and vocational services for people with psychiatric disabilities (and would thereby indicate service gaps) are 'integration of disability employment services with mental health care', 'intensive onsite workplace support', 'multidisciplinary teams to coordinate treatment and vocational interventions', and 'strategies to counter workplace stigma'.

Whilst avoiding a 'model-versus-model' scenario is recommended, it is also important to acknowledge that some consumers may not be in a position (or may not wish) to consider competitive or open employment. For them, a stigma-free work environment—such as those

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provided through sheltered workshops, transitional employment/clubhouse models, and social firms—may be desired to rebuild work and social skills and confidence.[145] Opportunities should be made available so that people with severe mental illness have available to them a range of different evidence-based employment programs, from IPS to more sheltered approaches.

Achieving education outcomes: what works?

Vocational rehabilitation that assists people in restoring illness-disrupted educational trajectories is also a part of a good practice approach to employment for people with severe mental illness, given the strong link between onset of illness and disruption to education/career development. Creating education opportunities can lead directly to improved opportunities for employment. Conversely, not addressing educational disruption 'can flatten potential career trajectories, constraining people to entry level employment or to lower paid, less skilled, less satisfying, and more labour intensive jobs.'[146]

Approaches include the supported education programs developed by the Centre for Psychiatric Rehabilitation, Boston University, in the early 1980s. According to Frost et al, the aim of such programs is 'to provide access to university or higher learning opportunities through a normal, non-stigmatising environment.'[147] There is no particular model that ties together supported education efforts; however, programs typically include the following elements:

- Academic and functional assessment.
- Assistance with career choices.
- Skills teaching (e.g. study skills, stress and time management).
- Utilisation of equipment (e.g. computers).
- Assistance in enrolment and access to campus-based services.

Supported education programs have been investigated extensively. Findings suggest that supported education is overall successful as a pathway to better employment outcomes.[148] Even though the attendance rates of those with psychiatric disabilities tend to ebb and flow over time

[145] Ibid., pp. 30-3. Further discussion on models of employment assistance can be found in a recent DEEWR review of employment assistance for people with mental illness. This review notes the variety of terms and concepts used to describe and evaluate different models for achieving employment outcomes. Many programs have been implemented internationally and nationally, and different names can sometimes refer to essentially the same approach. The review makes an attempt to place a number of models into six basic categories based on goals (e.g. open employment, sheltered employment, preparation for employment, self-employment), methods (e.g. IPS, clubhouses, 'train and place', etc.) and characteristics (i.e. services and sectors involved). See Commonwealth of Australia (2008) *Employment Assistance for People with Mental Illness*, op. cit., pp. 28-31.
[146] Ibid., p. 33.
[147] Frost et al, op. cit., p. 19.
[148] Waghorn and Lloyd, op. cit., p. 37.

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(commensurate with the episodic nature of their condition) studies show that those who persevere with programs achieve pass rates consistent with the mainstream student population.[149] Frost et al. also cite a review that demonstrates strong links between supported education programs and improved quality of life and educational/occupational status.[150]

There is emerging evidence too, that the 'zero exclusion' principle of the model of IPS used in evidence-based specialised supported employment programs can be successfully applied to supported education models. This involves not excluding anyone who says they would like to study and then providing them with the supports to do so successfully. As noted above, research shows that the principle of zero exclusion in specialised supported employment approaches results in higher rates of employment and satisfaction amongst people with psychiatric disabilities.

Good practice examples

ORYGEN Youth Health IPS Initiative

The Early Psychosis Prevention and Intervention Centre (EPPIC) at ORYGEN is a program that provides mental health treatment and care for young people with first episode psychosis.[151] The IPS initiative at ORYGEN saw the appointment of a full-time employment specialist to one of the two EPPIC teams. Clients receive assistance for 18 months followed by referral to adult mental health services for ongoing care. The employment specialist works with young job seekers independently of the existing employment system and external agencies.

ORYGEN conducted a randomised controlled trial of its IPS initiative over a six-month period involving 41 young people with first episode psychosis randomly allocated to the IPS and control groups.[152] Twenty people received assistance through IPS along with standard EPPIC treatment and 21 people received only the EPPIC treatment. The trial found that overall the IPS group had better employment outcomes than the control group.

Mental Illness Fellowship Victoria and St Vincent's Hospital Supported Employment Initiative

The Mental Illness Fellowship Victoria (MIFV) is a consumer organisation that has a contract with DEEWR to deliver disability employment services to inner-city residents with psychiatric disabilities.[153] MIFV established an evidence-based site at St Vincent's Hospital in 2006. This initiative saw the co-location of a full-time employment specialist with a capacity for 25 job seekers at the community-based mental health team at the hospital. The employment specialist is supervised through regular onsite visits by the MIFV Employment Coordinator. The two agencies have a formal Memorandum of Understanding and good cooperation has been achieved between the clinical team and the employment specialist.

[149] Frost et al, op. cit., p. 19.
[150] Ibid., p. 19.
[151] For this discussion, see Waghorn and Lloyd, op. cit.
[152] Killackey E (2007) 'Vocational intervention in first episode psychosis: A randomised controlled trial' Presentation to the 17th Annual TheMHS Conference as cited in Mental Health Council of Australia, op. cit., p. 41.
[153] For this discussion, see Waghorn and Lloyd, op. cit.

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Early indications are that the employment outcomes of consumers are exceeding expectations.[154]

Mental Illness Fellowship Victoria Training and Education Program

MIFV also runs accredited training and education courses.[155] These courses have been developed to meet the needs of people with severe mental illness. The 'Return to Learning and Self-Development Course' (Certificate in General Education for Adults) aims to ease students back into a learning environment, improve educational standards and acquire skills instrumental for future employment and achieving life's goals. The course is for people with severe mental illness who have aspirations for further study or employment, need career planning and guidance, or have support workers able to engage with MIFV to support them during the course. Students who do not have support workers are not excluded from enrolment.

MIFV hope to integrate their employment and education programs to a greater degree to create direct pathways to employment for people nearing completion of the course.

Bendigo Bank Disability Employment Program

Business and corporations in the private sector can play a key leadership role in changing community perceptions of people with mental illness through developing and implementing good practice programs that employ people with disabilities and contribute to improved workplace diversity. As noted in the discussion paper produced for the *National Mental Health and Disability Employment Strategy*, a comprehensive approach to creating supportive environments led by 'disability confident employers' will enable the attitudinal changes required for the recruitment and retention of people with mental illness in workplaces across Australia.[156]

In 2007, Bendigo Bank signed a Memorandum of Understanding with Disability Works Australia (DWA) to improve employment outcomes for people with a physical, intellectual or mental health disability.[157] Whilst Bendigo Bank does not monitor the numbers of people with disabilities coming through this program (it is, after all, up to the employees to disclose or not) there is an expectation that any workplace modifications required will be discussed with relevant managers/supervisors and responded to appropriately.

Good business outcomes have resulted from the new program. According to Bendigo Bank, there has been an overall increase in confidence with recruitment and a reduction in staff turnover. The main outcome reported is an attitudinal shift enabled by the program, with an expansion of people's minds to different possibilities.

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[154] Mental Health Council of Australia, op. cit., p. 41. MIFV subsequently established another site in Shepparton in the Goulburn Valley in partnership with DEN provider Worktrainers and the local state funded mental health service. This site also saw the collocation of a full-time employment specialist at the mental health service.

[155] For this discussion, see Mental Health Council of Australia, op. cit., p. 51.

[156] Commonwealth of Australia (2008) *National Mental Health and Disability Employment Strategy*, op. cit., p. 8.

[157] For this discussion, see Mental Health Council of Australia, op. cit., p. 54.

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Housing and Support: a platform for recovery
Background paper

Not just a house but a home

Many people living with severe mental illness experience significant socio-economic disadvantage such as financial dependency on income support and insecurity of housing tenure. This is evidenced by their demographic profile, which was captured through a census of 3,800 Australians aged 18 to 64 with psychotic disorders.[158] The research, undertaken by the Low Prevalence Study Group of the *National Survey of Mental Health and Wellbeing*, included interviews with 980 participants using a specifically designed instrument covering socio-demographic details such income and accommodation. The research found that 85.2% of those interviewed relied on a government pension or social benefit (in particular, the disability pension) as their main source of income. And whilst many lived in relatively stable forms of housing—such as public/private rental properties (31.4%), family homes (14.9%), their own homes (14.9%) or supported housing (2.6%)—a concerning proportion were housed in far more tenuous accommodation types. According to the study, 19.6% were in institutional settings, 13.6% were in hostels, and 8.8% were in other marginal forms of accommodation or were homeless.[159]

In their follow up bulletin to the census of people with low prevalence disorders, Harvey et al. suggest that special attention must be paid to those who are homeless or in marginal settings (here including hostels as well as boarding houses, hotel/rented rooms, emergency accommodation, shelters, no fixed address, etc.).[160] In the literature, the term 'iterative homelessness' has been developed to describe the repeated loss of stable accommodation and the movement through different forms of tenuous housing—a cycle that sometimes means not having a roof over one's head to sleep under at night ('sleeping rough' or primary homelessness).[161] The movement through tenuous housing may be short term (as in secondary homelessness) or ongoing and even permanent (as in tertiary homelessness). The notion of iterations of homelessness is useful because it captures the full set of homeless experiences that includes primary homelessness, but is not exclusive of secondary and tertiary contexts of being without a home.

Attention to the needs of people with severe mental illness caught in iterations of homelessness must be prioritised for at least three reasons. Firstly, consumers repeatedly identify stable housing as critical to their quality of life. In a recent survey of members conducted by the

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158 Jablensky A, McGrath J, Herrman H, Castle D, Gureje O, Morgan V and Korten A (1999) *People Living with Psychotic Illness: An Australian Study 1997-98*, National Survey of Mental Health and Wellbeing Report 4, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing. This study was part of the first National Survey of Mental Health and Wellbeing. The second National Survey of Mental Health and Wellbeing was conducted in 2007 with preliminary results available in late 2008.

159 Ibid., p. 33.

160 Harvey C, Evert H, Herrman H, Pinzone T and Gureje O (2002) *Disability, Homelessness and Social Relationships Among People Living with Psychosis in Australia*, National Survey of Mental Health and Wellbeing Bulletin 5, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing, p. 4 and p. 30.

161 Robinson, C (2003) *Understanding Iterative Homelessness: The Case for People with Mental Disorders*, Melbourne: Australian Housing and Urban Research Institute.

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Schizophrenia Fellowships of Australia, around two-thirds of respondents mentioned housing and housing support as the most important issues in their lives.[162]

Secondly, there is a strong association between housing stability and clinical improvement in people recovering from mental illness. The benefits of secure, safe and affordable housing for the general population are well documented. According to the World Health Organisation, these benefits go much further than merely providing a place of shelter. Not just a house, but a home, can foster a sense of belonging and self-worth. It is the place that supports participation in the social and economic life of the community.[163] For people living with severe mental illness, a home is especially important for promoting security, increasing quality of life, and reducing the risk of relapse and hospitalisation. In their paper, Meehan et al. cite several studies to support this. Some studies show that when assessed as stand-alone variables, stable housing is a better predictor of positive outcomes (i.e. not being hospitalised) than the existence of mental health services. Other studies show the negative effects of poor housing compared to appropriate housing and the improvement in overall functioning when consumers are moved from the former to the latter.[164]

Thirdly, access to adequate housing is a fundamental human right.[165] Without access to appropriate housing, people lose a base from which to build networks, hold down a job, and participate as citizens in their community.

Not just a house, but a home, for those with severe mental illness: this remains a significant challenge for governments at all levels as well as organisations supporting consumers and their carers/families. As noted in the groundbreaking report arising from a national inquiry into the human rights of Australians with mental illness:

> *One of the biggest obstacles in the lives of people with mental illness is the absence of adequate affordable and secure accommodation. Living with a mental illness—or recovering from it—is difficult even the best circumstances. Without a decent place to live it is virtually impossible.*[166]

Barriers to achieving housing

The high proportion of people living with severe mental illness and experiencing iterations of homelessness is well documented. Equally well documented is what appropriate housing looks like. Put simply, appropriate housing is housing that meets needs. It is stable and long term (not time limited), safe, affordable, chosen by the consumer, integrated into local communities, and

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[162] As cited in Mental Illness Fellowship Victoria (2008) *Mental Illness and Housing*, Preliminary Discussion Paper for Schizophrenia Awareness Week, Fairfield: Mental Illness Fellowship Victoria, p. 5.
[163] World Health Organisation (2004) *Review of Evidence on Housing and Health*, Background Document, Budapest: Fourth Ministerial Conference on Environment and Health, as cited in Mental Illness Fellowship Victoria, op. cit., p. 8.
[164] Meehan T, Stedman T and Robertson S (2007) 'The importance of housing for people with serious mental illness' in *Parity/New Paradigm*, Special Issue, Mental Health, Housing and Homelessness, p. 54.
[165] Harvey et al. op cit., p. 29.
[166] Burdekin B (1993) *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness*, Canberra: Australian Government Publishing Service, as cited in Harvey et al. op.cit., p. 29.

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ideally comes with supports. Though it may sound like we have the answers to housing, numerous barriers exist that prevent it from being realised for many consumers.

The 'housing affordability' crisis

Broader economic and social changes in recent years have seen the gentrification of older working class suburbs and a rapid decline of decent, affordable rental accommodation in inner city private rental markets. For those on lower incomes, the competition for affordable rental properties (especially single accommodation i.e. one bedroom) is intense. This poses particular challenges for people living with severe mental illness, often on lower incomes, looking for single accommodation, and needing to be near services and good public transport (i.e. in the inner city).[167] There is currently a very real danger of this group being further disadvantaged as they are squeezed out of the private rental market and forced to rely on other forms of accommodation. Included here are public and community housing as well as rooming houses and boarding houses, none of which are without issues for consumers.

The recently established National Affordable Rental Incentive (NARI) Scheme is intended to ease the pressure of rental costs by increasing the supply of affordable rental housing for low- and middle-income households. The scheme packages together a range of incentives (e.g. tax relief, planning concessions, financial subsidies) to encourage developers, investors and landlords to build and provide affordable rental properties. Whilst the scheme would make affordable housing achievable for many low- and middle-income households, complementary assistance—such as the Commonwealth Rent Assistance scheme or state-funded subsidies— would still be required for those who are very disadvantaged. Even with such assistance, there remain concerns that the NARI scheme won't make a difference to those experiencing extreme socio-economic disadvantage looking for housing in the private rental market, such as people living with severe mental illness.[168]

Just as worrying is the 'invisibilising' of this vulnerable group by the current public discourse on housing affordability with its focus on 'working families' in Australia's mortgage belts. The reality is that most people living with severe mental illness are far removed from this culturally dominant ideal of home ownership. A study by Lambert et al. shows that people with psychiatric disability are much less likely to own or be buying their home than the mainstream population (27% compared to 70% respectively).[169] The current climate therefore poses specific challenges for people living with severe mental illness. As noted by the Mental Illness Fellowship Victoria:

> *For those with responsibility for people with mental illness and their families, the challenge is to effectively advocate for the specific housing needs of this very disadvantaged group in the clamour of an urgent, dynamic and complex mix of needs.*[170]

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[167] Ilsley B (2007) 'Mental health, housing and the problem of supply', in *Parity/New Paradigm*, Special Issue, Mental Health, Housing and Homelessness, p. 70.
[168] Consultation with VICSERV Reference Group.
[169] Lambert G, Ricci P, Harris R and Deane F (2000) 'Housing needs of consumers of mental health services in rural Australia' in *International Journal of Social Psychiatry*, 46 (1): 57-66 as cited in Chesters J, Fletcher M and Jones R (2005) 'Mental illness recovery and place' in *Australian e-Journal for the Advancement of Mental Health*, 4:2, p. 2.
[170] Mental Illness Fellowship Victoria, op. cit., p. 5.

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Insufficient supply of appropriate housing

At the core of the failure to achieve housing for people living with severe mental illness is an insufficient supply of a range of appropriate housing types to meet demand. As discussed, the private rental market is becoming increasingly out of reach for many on low incomes, people with mental illness amongst them. But the public housing sector is equally incapable of responding to emerging needs with long waiting lists and depleted stock. Community housing managed by not-for-profit housing organisations is another option but is similarly in limited supply.[171] Successive governments have failed to adequately finance these social housing options with expenditure reduced every year since 1986. According to the Tenants Union NSW, in the ten years from 1996 the Commonwealth Government stripped more than $3 billion from funding to social housing, despite significant increases in the need for affordable rental accommodation due to upward trends in the housing market (such as gentrification).[172] Indeed, we have a situation today where the Commonwealth's rental assistance scheme is greater than its contribution to public housing.[173] Whilst rental assistance provides important relief to low income households in the private rental market, it is a 'demand side' response to that particular market, which sidesteps the core issue of the public housing supply.

Whilst supported housing has been shown to be very successful in providing an effective housing option for consumers, the fact is that there are not enough of these around. As revealed by the Low Prevalence Study Group research, supported housing was an accommodation type for only 2.6% of people with psychotic disorders participating in the study. Moreover, the supported housing that does exit tends to be program based within individual jurisdictions (e.g. the Housing and Support Initiative in NSW or the Housing and Support Program in Victoria—see 'Selected Models' below for more) rather than driven by systemic policy reform and funding across all jurisdictions within a coherent national framework for housing and mental illness.[174]

In Victoria, Supported Residential Services (SRS) offer accommodation to people experiencing disadvantage and requiring support with activities of daily living.[175] SRS can be described as a 'generic' approach to supported housing that includes people with mental illness in the client group. SRS are privately operated and regulated under the *Health Services Act 1988* and the *Health Services (Supported Residential Services) Regulations 2001*. They represent an important accommodation option for people living with severe mental illness—particularly through the recently introduced Supporting Accommodation for Vulnerable Victorians (SAVVI) Initiative (since 2006). Funded through the Department of Human Services (DHS), SAVVI seeks to assist pension-level SRS to improve their financial viability and capacity to meet the support needs of residents. Facility cost relief for proprietors and coordination of support services for residents are amongst the key features of SAVVI.

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171 Ilsley, op. cit., p. 70. See also Smith A and Stylli T 'Where do you go when your last resort has closed?' in *Parity/New Paradigm*, Special Issue, Mental Health, Housing and Homelessness, pp. 59-60. It is noted that community housing offering shared or group accommodation for people with severe mental illness is not always an effective option, given specific needs related to a range of behavioural and cognitive deficit symptoms that would not be met by such arrangements.

172 Tenants Union NSW available at http://www.tenants.org.au/publish/social-housing/index.php and accessed 21/07/08.

173 Commonwealth of Australia (2008) *Which Way Home? A New Approach to Homelessness*, Green Paper, Canberra: Commonwealth Government Department of Families, Housing, Community Services and Indigenous Affairs, p. 41.

174 Wilson, J (2007) 'Towards inter-sectoral support models in mental health' in *Parity/New Paradigm*, Special Issue, Mental Health, Housing and Homelessness, pp. 22-3.

175 State Government of Victoria (2008) *Review of the Regulation of Supported Residential Services in Victoria*, Discussion Paper, Melbourne: Victorian Government Department of Human Services.

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… And the increasing use of inappropriate housing by default

Rooming house accommodation involves residents renting bedrooms with access to shared common facilities such as bathrooms, kitchens and laundries. Rooming houses do not provide meals to tenants whereas boarding houses (which, like private rentals, are becoming increasingly rare due to inner city gentrification) include at least one meal a day. Rooming houses can be privately owned (sometimes called 'private hotels') or publicly owned and managed through community organisations. In Victoria, for example, DHS funds a Rooming House Program.

Rooming houses were never intended to be used as emergency or supported accommodation but are rather an option for single people (traditionally older males) seeking long-term housing options. Recent studies, however, show that rooming houses are today being used in much more complex ways by people with very high needs, including those with severe mental illness. A recent report on rooming houses in the City of Yarra, reveals that agencies in the area actually view rooming houses as a form of crisis or transitional housing for their clients. The report goes on to suggest that rooming houses are increasingly becoming part of the homelessness service system even though they are not resourced to provide adequate levels of support; nor can they 'fill the gaps' in the crisis and transitional housing system.[176]

In Victoria, time limited transitional and emergency housing is available for those who find themselves homeless (or at risk of becoming homeless) through the Transitional Housing Management Program and Supported Accommodation and Assistance Program. Because of an acute shortage, transitional and emergency accommodation can serve only a fraction of the homeless population at any given time. To address the shortfall, some housing workers have no choice but to draw on other forms of accommodation for their clients, such as rooming and boarding houses. There is evidence to suggest that for people living with severe mental illness, this form of accommodation is highly inappropriate (even traumatising). Chesters et al. note that boarding houses are often associated with increased use of alcohol and other drugs by occupants and increased exposure to violence.[177] Other research shows that the longer one stays in these types of marginal accommodation, the more 'acculturated' one becomes to the environment and the slimmer the prospects for regaining housing (and all the benefits this brings).[178] Yet, marginal accommodation is the main housing experience of many living with severe mental illness. And this situation is often enduring with only a small number ever achieving an improvement in their housing security.[179]

With so little on offer in terms of appropriate housing for this client group, many find themselves living with their parents for extended periods of time. This adds another level of concern: that of ageing parents who provide huge amounts of care to their adult children and the options that are left for consumers when inevitably (and sadly) these supports are gone.

[176] Yarra Community Housing (2002) *No Place Like Home: Issues and Challenges for Community Managed Rooming Houses in the City of Yarra*, Fitzroy: Yarra Community Housing.
[177] Chesters et al., op. cit., p. 2.
[178] Chamberlain C, Johnson G and Theobald J (2007) *Homelessness in Melbourne: Confronting the Challenge*, Melbourne: Centre for Applied Social Research, RMIT University, p. 11.
[179] Mental Illness Fellowship Victoria, op. cit., pp. 14-15.

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The important point that must be made about the use of any or all of these accommodation types is that they are not really appropriate housing options for people with severe mental illness. As stated previously, what consumers need most of all is housing that meets their needs, that is, housing that is stable, long term, chosen by them, safe, affordable, and with access to supports. Indeed, an argument can be made that as long as these housing types are considered 'options' for consumers, attention to the real issue—that of providing appropriate housing to a vulnerable group in our community—is conveniently avoided.

System failure

Insufficient supply contributes to system failure, that is, the failure on the part of the service system to find timely appropriate housing for those in need and intervene early before an episode of homelessness becomes the start of a repeating cycle. Take, for example, a person who is hospitalised because of their mental illness. This person may fall behind on rent and may lose their private rental property as a result. They might remain 'stuck' in the acute system for longer than necessary because supported housing cannot be found (or isn't available) thereby contributing to the problem of 'blocked beds'.[180] There is currently an estimated 40% or more of acute mental health patients who could be discharged if there existed appropriate housing and supports.[181] Or, they might be discharged into marginal accommodation with the prospect of dealing with their ongoing housing needs later on.[182] This unblocks the beds and relieves some of the pressure experienced by an over-burdened acute system, but doesn't address the consumer's needs for housing and can inadvertently contribute to the cycle of homelessness. This consumer can find themselves back in the acute system because their resulting homelessness has exacerbated their mental health problems or there is nowhere else to go—or both. As noted by a mental health clinician:

> *There's a real revolving door syndrome – people get admitted, they get treatment and then they get discharged but because there's no supported accommodation for them they keep coming back into hospital.*[183]

There are serious economic consequences of this 'revolving door' syndrome. The estimated average recurrent cost of providing one mental health hospital bed is around $150,000 per year (2002-2003 figure) compared to one unit of public housing at $5,990 per year (2006-2007 figure).[184] Carr et al., in their cost-of-illness study of psychosis, conclude that we appear to be spending a disproportionate amount on 'housing' people in hospitals (or prisons, see below) without sufficient investment in appropriate (supported) housing options in the community.[185]

System failure is also the direct result of sector isolation and a lack of integration between mental health policy and housing policy. Currently in Victoria, an estimated 10% of Psychiatric

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[180] Ilsley, op. cit., p. 71.
[181] Commonwealth of Australia, op. cit., p. 42.
[182] Henderson S (2003) 'Mental illness and the criminal justice system', Rozelle: Mental Health Coordinating Council available at http://www.mhcc.org.au/projects/Criminal_Justice/ and accessed 04/07/08.
[183] Mental Health Council of Australia (2005) *Not For Service: Experiences of Injustice and Despair in Mental Health Care in Australia*, Canberra: Mental Health Council of Australia, p. 179.
[184] Mental Health Coalition of South Australia (2008) *Housing for Mental Health: 2008-2012*, Adelaide: Mental Health Coalition of South Australia, as cited in Commonwealth of Australia, op. cit., p. 42.
[185] Carr V, Neil A, Halpin S and Holmes S (2002) *Costs of Psychosis in Urban Australia*, National Survey of Mental Health and Wellbeing Bulletin 2, Canberra: Mental Health Branch, Commonwealth Department of Health and Ageing, p. 35.

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Disability Rehabilitation and Support Services (PDRSS) clients (around 1,200 people) are recorded as living in unstable or transitional housing. An estimated 5% of clinical mental health services clients (around 3,000 people) are homeless or at risk of homelessness. An estimated 25% of clinical mental health services clients (around 9,600 people) have identified unmet needs for more stable forms of accommodation.[186] These people require immediate assessment and assistance to determine their level of need and provide referrals. The reality is that this does not always happen, and mental health and housing services do not always work in partnership to share resources, skills and knowledge in order to respond expeditiously to the needs of their consumers. As Harvey et al. note, even the best clinical services will fail to meet the needs of those with the most complex needs unless there is close cooperation with housing and other services (welfare, disability support, and vocational) to provide support and assistance to each individual.[187]

Further sector isolation exists between mental health, housing services and the criminal justice system adding to system failure. What is needed is sound collaboration between these sectors so that police have different alternatives to hospitalisation or arrest. Instead, police are often called in to manage a mental illness crisis and required to make an assessment of a person's mental health status before referring them to hospital… or remand. When faced with a critical shortage of facilities for treating people with mental illness in the acute setting, police have little choice. As noted by the President of the Police Association of New South Wales:

> *Where do we take people? Where do we put people? How do we care for them in some real way so that they are not out in the streets? The reality is that people are getting charged with criminal offences where really we should be applying another section to take the opportunity to deal with psychiatric illness.*[188]

It is a sad truth that prison is 'home' for increasing numbers of people with severe mental illness who find themselves incarcerated for criminal behaviour as a consequence of a range of interlocking factors. These include poverty, marginalisation, homelessness, and substance use issues co-occurring with their mental illness, but perhaps most of all, a service system that has failed them.

The result is an over-representation of people with severe mental illness in the prison population. In their study on the prevalence of mental illness in the New South Wales prison population, Butler and Allnutt found a 12-month prevalence rate of 74% for 'any psychiatric disorder' e.g. psychosis, anxiety disorder, affective disorder, substance use disorder, personality disorder, or neurasthenia. The 12-month prevalence rate for these disorders in the non-prison population is around 22%. The authors also found a higher prevalence of psychiatric disorders amongst female prisoners compared to their male counterparts. And whist the most common group of mental disorders in the prison population was anxiety disorders, the study revealed a 12-month prevalence rate of psychosis at 9%—a figure that is 30 times higher than the non-prison population.[189]

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[186] State Government of Victoria (2008) *Because Mental Health Matters: A New Focus for Mental Health and Wellbeing in Victoria*, Consultation Paper, Melbourne: Victorian Government Department of Human Services, p. 32.
[187] Harvey et al., op. cit., p. 54.
[188] As cited in Henderson, op. cit.
[189] Butler T and Allnutt S (2003) *Mental Illness Among New South Wales' Prisoners*, Matraville, NSW: NSW Corrections Health Service, pp. 2-3.

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Limited or no support

For those who do achieve stable housing, a range of issues around referrals needs to be addressed such as links to a general practitioner, chemist and mental health service. Then there are general issues like finding the local supermarket or nearest bank and working out the public transport system. There is time limited support for people in transitional housing moving into public housing, and of course ongoing support is a feature of the small numbers of supported housing that exist. But otherwise ongoing support for consumers is non-existent. Without support, many people living with severe mental illness can find themselves not able to maintain their housing and back into iterations of homelessness. As Chamberlain et al. write:

> *Homelessness cannot be resolved without housing, but on its own housing is insufficient to prevent the reoccurrence of homelessness for some people. […] A more realistic approach to the provision of long-term support is necessary. This has to recognise that most people take time to rebuild their lives after returning to stable housing.'*[190]

Stigma

People living with severe mental illness feel the effects of stigma a daily basis. With respect housing, they are frequently exposed to discrimination from landlords, neighbours and the wider community making stable housing not only difficult to achieve but hard to maintain.

Effective housing: what works?

What are the factors that contribute to effective housing for people with severe mental illness? The availability of supports is critical e.g. informal networks, appropriate clinical treatment, psychosocial rehabilitation, disability support etc. These supports are flexible and individualised, given at the outset of tenancy, and ongoing (time unlimited) after housing is established. Having a key worker or case manager to coordinate supports is also important.[191] These ingredients combine into what is known as supported housing. The fundamental premise of supported housing is that people living with severe mental illness are no different to everyone else in their needs for secure housing, it is just the level of support that is different.

There is evidence internationally and in Australia of a range of supported housing models that work. There is also evidence that shows significant cost savings as consumers who are securely housed with access to supports and services that they need are less likely to repeatedly return to hospital emergency departments for crisis care.[192] These models may have different stakeholders, partnerships and tenure arrangements, but they do share in common the following key elements:[193]

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[190] Chamberlain et al., op. cit., p. 36 and p. 44.
[191] Mental Illness Fellowship Victoria, op. cit., p. 11.
[192] HomeGround Services (2008) 'HomeGround supportive housing: Ending homelessness in Melbourne', Collingwood: HomeGround Services, p. 5.
[193] See for example Mental Illness Fellowship Victoria op. cit.

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- An explicit focus on people recovering from severe mental illness.

- An orientation towards the whole person in all their complexity.

- The provision of secure and ongoing tenure in appropriately designed and located housing stock.

- Comprehensive and coordinated ongoing support tailored to individual needs.

Meehan et al. write that the provision of supported housing represents a new way of thinking about housing with wrap around supports, and includes several core requirements.[194] These requirements were first outlined by Ridgeway and Carling but have been developed by many contributors over time.[195]

- The house must be a home (not a 'residential treatment setting').

- Housing must be stable and long term (not time limited) to break into iterations of homelessness.

- Choice of housing must be based on consumer preference.

- Consumers must be housed as members of the community, not residents of a program.

- Housing should foster consumer control of their environment.

- Housing that keeps levels of stress manageable should be selected.

- Housing should be located in neighbourhoods with a mix of residents (consistent with community norms) to minimise stigma.

- Housing must have an appearance consistent with the neighbourhood.

- There must be support available that is individualised and flexible.

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[194] Meehan et al. op. cit., p. 56.

[195] Ridgeway P and Carling P (1987) *Strategic Planning in Housing and Mental Health*, Boston: Centre for Community Change through Housing and Support.

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- The levels of support required at any given time must be defined by consumers.

- Support must occur in the person's home (rather than in a transitional environment).

The UNSW Consortium has recently developed a paper for the Queensland Government to guide future policy directions for people with psychiatric disabilities. To the above requirements can be added the following:[196]

- Services must be responsive to the needs of different population groups e.g. indigenous communities, culturally and linguistically diverse communities, younger people, older people, people with complex co-morbidities including dual diagnosis and substance use disorders.

- There should be a separation of housing and support services either by different providers or different functions within the one organisation to minimise conflict and ensure integrity of service delivery.

- There must be interagency collaboration between housing providers, support providers, clinical services, government and other services relevant to the client group.

- There must be ongoing advocacy to address stigma and discrimination experienced by people living with severe mental illness in their neighbourhoods and communities.

Selected models

The following programs reflect successful models of supported housing. They each meet many of the requirements identified above.

Housing and support program (HASP) Vic

HASP, established in the early 1990s, saw two areas of the Department of Human Service— the Mental Health Branch and the Office of Housing—working alongside the emerging PDRSS sector to deliver housing and support programs to people with psychiatric disabilities across Victoria.[197] There are currently around 1,200 public housing properties allocated to HASP with psychosocial rehabilitation and support provided through PDRSS.

[196] UNSW Consortium (2008) 'Principles for effective housing and associated support for people with mental illness or psychiatric disability' available at http://www.sprc.unsw.edu.au/SummaryEffectivenessFactors11March.doc and accessed 04/07/08.
[197] Chesters et al. op. cit., p. 3.

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Evaluations of the program in its early days showed that residents enjoyed 'increased wellness, characterised by such measures as reduced hospital stays'.[198] Chesters et al. have more recently evaluated a housing and support provider responsible for 23 HASP properties in regional Victoria—SNAP Gippsland Inc.—with similar positive results. They write that for the residents of SNAP, 'there is a home and even if they need to go to hospital for a time, there will be a place to return to when things are better.'[199] Despite its success, HASP (according to some) has largely lost its identity and has not been sustained because housing stock has not been replaced. The program is currently in need of a re-energised policy and funding effort.[200]

Whirrakee Housing and Support Service 'Mental Health Pathways' Vic

The Whirrakee Housing and Support Service in Bendigo provides a range of housing and support services including a 'Mental Health Pathways' program.[201] This program, which was piloted through the Victorian Homelessness Strategy and has since been rolled out to other areas in Victoria, engages consumers at the point of discharge from hospital to prevent them from entering homelessness.

Consumers assessed as at risk of homelessness are moved into a crisis unit. They are provided with support through a worker who explores housing pathways, assists in navigating the system, and works with them on securing long-term housing and other aspects of recovery. In addition to the crisis unit, Whirrakee has nine transitional properties attached to the program and nomination rights on a number of Office of Housing properties through HASP. Importantly, there is ongoing outreach into community properties once residents have moved into long- term housing.

NEAMI/Supported Housing Ltd Initiative Vic

NEAMI and Supported Housing Ltd have partnered since 1995 to deliver long-term housing and support to people with a history of institutionalisation in Melbourne's northern suburbs.[202] Secure and affordable housing is provided by the Office of Housing with tenancy managed by Supported Housing Ltd. Psychosocial rehabilitation support is provided through NEAMI as a specialist PDRSS. Clinical support is provided by community-based mental health services.

Key factors of success include the location and type of properties, management of issues around sharing and living alone, a commitment to ongoing tenure, and practices around tenancy management. A recent evaluation of this initiative showed many people successfully housed in their communities with ongoing support after years spent in psychiatric hospitals.

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198 Robson, B (1995) *Can I call this home? An evaluation of the Victorian Housing and Support Program for People with Psychiatric Disabilities*, Melbourne: VICSERV as cited in Chesters et al. op. cit., p. 3.
199 Chesters et al., op. cit., p. 8.
200 Ilsley, op. cit., p. 71.
201 Bennett S (2007) 'The experience of a psychiatric disability specific housing service' in *Parity/New Paradigm*, Special Issue, Mental Health, Housing and Homelessness, pp. 45-7.
202 Carter M (2007) 'After the institution: What next?' in *Parity/New Paradigm*, Special Issue, Mental Health, Housing and Homelessness, pp. 57-8.

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Housing and Support Initiative (HASI) NSW

HASI is a partnership between the Department of Health, the Department of Housing, and non-government organisations (e.g. community housing providers, area mental health services and providers of psychosocial rehabilitation).[203] The model operates within a recovery framework to assist people with psychiatric disabilities to participate in the community, maintain successful tenancies, and improve their quality of life. HASI was established in 2002-2003 and currently supports more than 100 consumers with complex mental heath needs.

A recent two-year evaluation of HASI undertaken by the Social Policy Research Centre, UNSW, found that with appropriate support consumers 'can live independently in stable, safe, affordable homes.'[204] HASI has also demonstrated improvements in mental health (e.g. fewer rates of psychiatric and emergency admissions or shorter durations of such admissions) and increased social and economic outcomes (e.g. participation in paid employment and other vocational activities). According to the evaluators, these benefits well and truly offset the recurrent annual cost of the program of around $58k per person.[205]

Project 300 Qld

Project 300 was an initiative that commenced in 1995 to assist 300 people with psychiatric disability to move from institutional care into housing of their choice in the community. The project involved a partnership between three government departments (Public Works and Housing, Family Services, and Health). Each client on discharge was provided with a 'package' of services including accommodation, disability support, and mental health. Each package was tailored to the specific needs of individual consumers and the emphasis was on consumer involvement in selecting the housing that was right for them in properties that were indistinguishable from others in the neighbourhood.

Meehan et al., in their paper on Project 300, write that consumers appreciated the opportunity to be involved in the selection of their accommodation and that it reduced the stress of leaving hospital. The establishment grant of $5,000 that came with the package increased consumers' sense of control over their environment. The support provided by mental health professionals and disability support workers was also viewed as appropriate to meeting their needs.[206]

HomeGround Supportive Housing Initiative Vic

This initiative is being implemented in Melbourne during 2008 and is targeted to the primary homeless population, people with severe mental illness amongst them. The initiative will offer safe, permanent and affordable housing and onsite support services to help tenants settle into and maintain their housing, and will ensure a mix of tenants to enable a thriving and diverse community within a single site development at 660 Elizabeth Street in Melbourne.

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[203] Muir K and Fisher K (2007) 'Stable housing: The foundation of improved mental health' in *Parity/New Paradigm*, Special Issue, Mental Health, Housing and Homelessness, pp. 50-3.
[204] Ibid.
[205] Muir K (2008) 'Housing support for people with mental illness', in *Social Policy Research Centre Newsletter* (March) as cited in Mental Illness Fellowship Victoria op. cit., p. 19.
[206] Meehan et al., op. cit. pp. 54-6.

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The HomeGround Supportive Housing Initiative model consists of five interdependent elements: property management, tenancy management, onsite support, safety (controlled access), and community integration. HomeGround has developed (or is developing) partnerships with a number of agencies in the homelessness service sector, mental health service sector, and corporate and philanthropic sectors. Strong partnerships have already been formed with the Office of Housing, Yarra Community Housing, City of Melbourne and Grocon to progress the initiative thus far.[207] HomeGround will deliver onsite support services and work in partnership with key agencies to broker provision of other services across the different elements.

The initiative is based on internationally proven and recognised approaches that address the complex needs of the primary homeless population, such as *Housing First* in New York City. The *Housing First* model prioritises consumer choice for housing first, not after, or as a condition of, treatment. Once housed, consumers continue to choose the supports and services they need. There is a clear separation of housing and treatment elements: tenants must pay rent and observe the rules of a standard lease and relapse does not mean housing loss. There is an emphasis in recovery with secure housing and individualised and flexible services/supports as critical to this process.

The *Housing First* model has been replicated across North America resulting in tens of thousands of supportive housing units developed and operated by non-profit organisations. As noted by HomeGround, the *Housing First* model:

> *… has evolved significantly over the past 20 years into a dynamic, flexible and robust model, which meets the unique needs and characteristics of specifically marginalised homeless populations. While cost-effective, the greatest outcome has been in human terms for individuals, families and the communities in which they live.*[208]

Clearly, various models of supported housing can be drawn upon nationally and internationally that have successfully helped consumers to achieve and maintain secure and affordable accommodation. The issue as far as housing is concerned is not so much about which model to choose, but rather the policies and level of funding required to increase and sustain supported housing options. With only 2.6% of consumers living in supported housing and a much higher proportion trapped in iterations of homelessness and 'revolving' through the mental health, crisis accommodation and criminal justice systems, there is an urgent call to governments across all jurisdictions and organisations across several sectors to respond to the specific housing needs of this marginalised and disadvantaged group.

[207] Grocon has agreed to build the facility at cost, representing a corporate donation of around $15 million. See Commonwealth of Australia, op. cit., p. 60.
[208] HomeGround, op. cit., p. 6.

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There is currently a significant process in place for tackling homelessness under the banner of the Federal Government's new social inclusion agenda. *Which Way Home? A New Approach to Homelessness* is a green paper that puts forward options for responses to homelessness including a greater focus on prevention and early intervention for population groups at risk.[209] The white paper to follow will include a national action plan to reduce homelessness in the lead up to 2020. It is critical that this national action plan includes options to progress a specific housing and supports agenda for people living with severe mental illness, lest they become further 'invisibilised' by mainstream discourses on affordable housing and homelessness.

[209] Commonwealth of Australia, op. cit.

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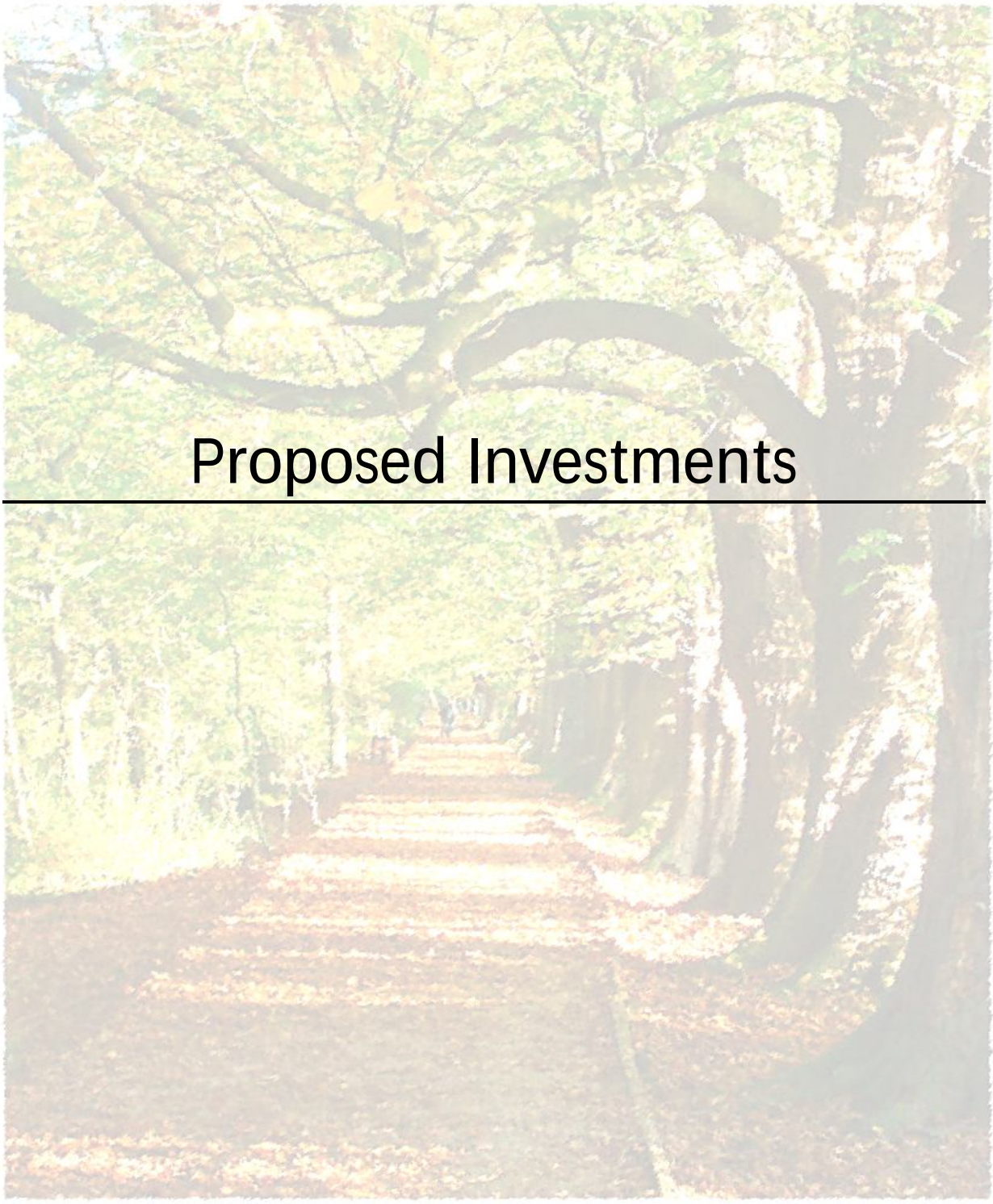

Proposed Investments

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Consolidated Table of Propositions

Strategy Element	Initiative	Year 1	Over 3 Years	Funders and Contributors	Outcomes
Health Inequalities: policy and practice failure					
Research	Research partnership(s), prioritised agenda, seed funding	$150,000	To be determined	DHS and/or C'wealth	Better evidence of need, and impact; guide to effective practice
Practice Innovation	Pilot integrated PDRSS/ primary health responses (x 6 plus evaluation)	$1,950,000	$5,550,000	DHS Mental Health and Primary Care Branches and/or explore potential partnership with C'wealth	Improved primary health response to target group, better linked sectors, good practice, evidence
	Targeted health promotion/prevention initiative	$100,000	To be determined	DHS with possible VicHealth partnership	Targeted health promotion model; enhanced consumer engagement, better linked sectors and extended partnerships
	Review of all PDRSS program types for 'whole of person health approaches'	Existing resources	Existing resources	VICSERV	Good practice evidence, gap analysis, better integrated program design
Workforce Awareness and Development	PDRSS sector Health Awareness Training Program	$40,000 plus existing resources	Existing resources	DHS/ VICSERV	Increased awareness and changed mindsets, improved health needs identification and better integrated PDRSS program design features
	Beyond Mental Illness Training Program for mental health clinicians and GPs	To be determined	To be determined	To be determined	Increased awareness and changed mindsets, improved health needs identification and service responsiveness

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Housing and Support: a platform for recovery					
Visibility and Voice	Economic modelling	$60,000	To be determined	Seed funding DHS, longer term to be determined	Evidence base for investment
	Ageing carers and housing risk	$60,000	-	DHS or C'wealth	Risk identified and understood
	'Discharge to where?' snapshot	Existing	-	VICSERV/ DHS	'Quick' overview of immediate need

Strategy Element	Initiative	Year 1	Over 3 Years	Funders	Outcomes
Planned and Integrated Approach	Housing needs forecasting	$120,000	To be determined	DHS	Knowledge of need over time. Capacity to take a planned approach
	Opportunity audit	$75,000	-	DHS	Viable opportunities identified and scoped
	Mental Health Alliances – Focus on housing and support	Nil	-	Existing forum and resources	Increased awareness, local responsiveness
Innovation and Expansion	Housing linked support	To be determined	To be determined	DHS – potential C'wealth partnership	Rebalanced system – better consumer outcomes
	Workforce needs analysis	Existing	-	Ministerial Advisory Group, DHS, VICSERV	Balanced and effective approach to workforce planning
	Capital investment for innovation and to meet need	To be determined	To be determined	C'wealth, State, housing providers	Long term solution and platform for recovery in place – better outcomes
	Limited-life social housing subsidy scheme	To be determined	To be determined	DHS, C'wealth, others	Current crisis responded to in the short to medium term

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Economic Participation: employment and education – changing outcomes					
Targeted Policy	Education and employment – intersectoral alignment; targeted policy and strategy	No additional resources, commitment leadership and dialogue	Not known	Leadership + participation at C'Wealth and State levels	An aligned change agenda that supports education and employment outcomes
Actions to Make a Difference Now	New model of support: 'flexible hours support program'	$20,000 in seed funding; VICSERV in-kind contribution (equivalent value)	To be determined	DHS Mental Health Branch and VICSERV	Tailored support model that enables consumers to achieve better education and employment outcomes
	Peer workforce	$100,000 x 6 + $60,000 (evaluation) = $660,000	(Year 2) $100,000 x6 + $60,000 evaluation= $660,000	DHS, DPCD, VICSERV (and members) and others	Expanded peer workforce, good (OD) practice models

Strategy Element	Initiative	Year 1	Over 3 Years	Funders	Outcomes
Organisational Capacity Building	Training Program: Enabling Employment and Education	$60,000	-	VICSERV and members, selected providers	Attitudinal change amongst professional and a training resource for ongoing use
	Workplace Ready Team	$300,000	$300,000	C'wealth and State Governments VicHealth, VICSERV, employment Services	Increased number of employers, committed and ready to provide sustainable employment for consumers
Evidence-Based Practice	Education: Experience, Aspirations and Outcomes Study	$30,000 to design	$90,000 to complete	DHS, VICSERV, consumers and others	Increased understanding of how to build capacity for better educational outcomes
	Impact Study of Caring on Employment and Education	$60,000	To be determined	DHS, VICSERV and carer organisations	Increased understanding of the impacts of the role of carer on education and employment

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