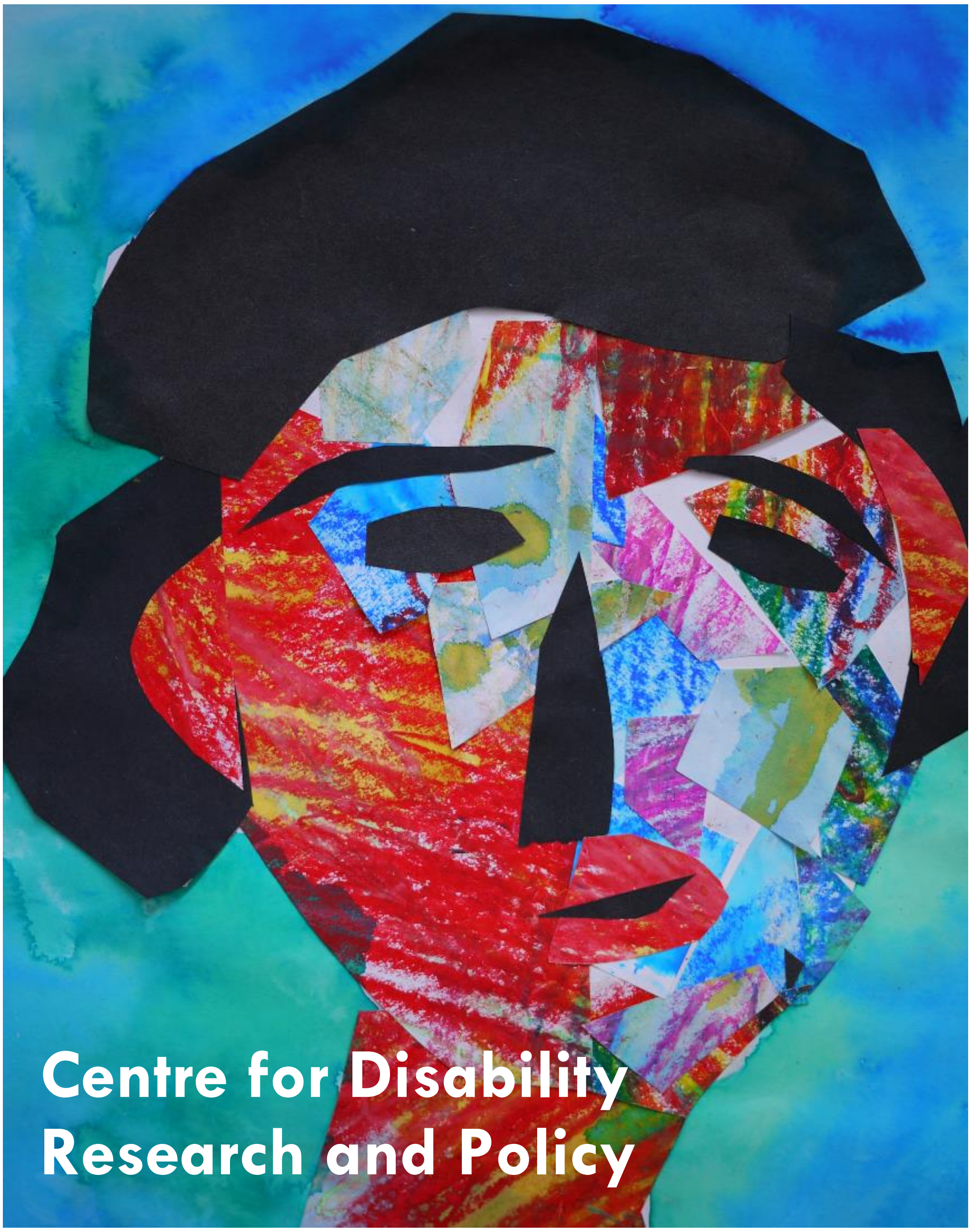
# Submission to the Productivity Commission Inquiry into the economic impacts of mental ill-health.

Response to the Issues paper the Social and Economic Benefits of Improving Mental Health.



Centre for Disability Research and Policy

# Submission to the Inquiry into the economic impacts of mental ill-health:

## Responding to the Issues paper on the Social and Economic Benefits of Improving Mental Health

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## Introduction

This submission applies the current work of the Centre for Disability Research and Policy to the Issues paper on the Social and Economic Benefits of Improving Mental Health.

The release of the *Issues Paper* was particularly welcome. As noted in the document, mental illness is common with four million people having experienced a common mental disorder in 2014-2015. This is an alarming number of Australians, but I think it detracts from the fundamental importance in understanding that population health strategies should by their nature apply to the population as a whole. We all have mental health – sometimes it is good and sometimes it is not good and sometimes we need a small amount of help or a great deal of help in many parts of our lives to improve it. While this paper acknowledges that there are significant flow-on effects of good mental health, this is not something that just applies to people who have experienced mental ill-health – it applies to all Australians. The more that we can encourage all Australians to think about themselves in relation to mental *health*, not just *ill*-health, then the more we can understand that mental health is everyone's business and move towards a more holistic national approach to mental health.

International examples of population mental health strategies have shown that in order for them to be effective there needs to be a whole-of-government approach that works on cutting across government silos and artificial boundaries (such as those imposed by Local Health Districts, discussed below). Good examples of population mental health strategies from the past 10 years include those by the Scottish Government (e.g. *Towards a Mentally Flourishing Scotland*) and the English Government's *Prevention Concordat for Better Mental Health*.

In creating this submission I have focused in on providing a summary of several projects whose findings can draw attention to some of the key questions structuring the issues paper. Further information on all of these projects is available on request. I have only commented on those questions for which I have relevant and tangible information to answer. This submission focuses on the following specific question groups:

1. Structural Weaknesses in Health Care
2. Comorbidities and Specific Health Concerns
3. Questions on Justice
4. Questions on service gaps – particularly relating to the NDIS
5. Questions related to education, training and employment

## Responses to questions in the issues paper

### Specific questions on Structural Weaknesses in Health Care

There are ongoing fundamental structural weaknesses around system connectedness, particularly relating to people with complex needs.

Partners in Recovery (PIR) was a Gillard-government initiative which was put in place in Medicare local and subsequently PHNs across Australia. They were run by consortia of local NGOs and government organisations and aimed to put in place a system of support facilitators who would connect the system around an individual with complex needs and buy in supports when needed. This was a good system because it was localised, had flexible funding which could be drawn on with minimal rules around expenditure (unlike the NDIS) and was adaptable to circumstances of acute illness in that funds and services could be provided quickly as needed. It had good recovery-oriented outcomes for clients. Our 3-year evaluation of PIR in two regions in Sydney showed that the program was successful in meeting client's psycho-social needs and improving recovery.

The funding for PIR was earmarked for the NDIS and the program slated to close as all clients were expected to transition into the NDIS. Our *Mind the Gap* report into the NDIS and psycho-social disability showed that this was not the case. PIR is ongoing in several regions as the Federal Government has recognised that many of the PIR clients have not successfully transitioned in the NDIS. The lack of flexible funding associated with the NDIS, and the lack of support coordination as standard in plans has meant that many of the benefits of the PIR approach have been lost when clients have transitioned to the NDIS.

We are currently carrying out a project funded by the National Mental Health Commission which is tracking these transition rates across Australia. Data from this project should be available mid-year and is available on request.

Our evaluation of PIR is published in several journal articles and conference proceeding papers:

1. Smith-Merry, J. Gillespie, J., Hancock, N. and I. Yen (2016) Facilitating recovery in a complex setting? The role of Support Facilitators in achieving the Partners in Recovery outcomes. *2015 TheMHS Conference Proceedings*. Translating Best Practice into Reality 25-28 August 2015 Canberra, ACT.
2. Smith-Merry, J., Gillespie, J. (2016). Flexible funding for effective, individualised, integrated care. *4th World Congress on Integrated Care*, 23rd – 26th November. Wellington, New Zealand.
3. Smith-Merry, J., J. Gillespie, N. Hancock and I. Yen (2015) Doing mental health care integration: a qualitative study of a new work role, *International Journal of Mental Health Systems*. 9(32).
4. Smith-Merry, J., Gillespie, J. (2016). Embodying policy making in mental health: the implementation of Partners in Recovery. *Health Sociology Review*, 25(2), 187-201.
5. Hancock, N. Smith-Merry, J, Gillespie, J Yen I (2017) Is the Partners in Recovery program connecting with the intended population of people living with severe and persistent mental illness? What are their prioritised needs? *Australian Health Review*, 2017, 41, 566–572
6. Hancock, N. Scanlan, J, Gillespie, J. Smith-Merry J. (2017) Partners in Recovery program evaluation: changes in unmet needs and recovery. *Australian Health Review,* 42(4), 445-452.

## Comorbidities and specific health concerns

The answer to this section draws on research from an in-depth analysis of unintentional deaths of people with serious mental illness investigated by the Coroner (2012-2016). Our research has found that there are very high numbers of deaths related to drug and alcohol use, cardiovascular disease, infections, accidents and metabolic disorders. For drug-related, embolism, drowning and obesity-related deaths, the rate amongst people with serious mental illness was far higher than the NSW average.
These figures highlight:

- the need for a much more nuanced and targeted physical health strategy for people with mental illness. Given the very high rates of sedentary behaviour related deaths in this group, there should be a focus on physical exercise programs, such as those provided through programs of social prescribing. This has been used and with good effect in the UK for over 15 years but has been very slow to be taken up in Australia.
- The importance of services which specifically target drug and alcohol interventions for people with mental illness (and vice versa). Currently these areas still work within their own silos.
- The need for a drug and alcohol strategy specifically for people with mental ill-health.

**Summary of report findings (full report available on request):**

In NSW there were 1302 unintentional deaths amongst people with serious mental illness and 3293 intentional deaths recorded in the Coronial system over the years 2012-2016 which are available for analysis. An analysis of the qualitative and the quantitative data show that on the whole people with serious mental illness are living marginal lives disengaged from the broader community. They are often living highly isolated lives with little contact with the wider community. They were socially isolated and often lived in inappropriate housing. Very few people were employed (10%).

**Cause of death**
The data analysis shows that in deaths that were not suicide – called 'unexpected' or 'unintentional' mental health related deaths[1] - people die from a range of mainly preventable conditions and incidents. The data shows that people are most likely to die from drug and alcohol and from cardiovascular disease.
When categorised, the primary (direct cause of death) causes of death can be refined to:

- Drug and/or alcohol use (total deaths: 519)
- Cardiovascular disease (total deaths: 310)
- Acute and chronic infections (mainly lung, liver) (total deaths: 110)
- Metabolic or sedentary behaviour-related (obesity, diabetes pulmonary embolism) (total deaths: 104)
- Accidental deaths (e.g. drowning, choking, strangulation, electrocution, car accident) (total deaths: 102). This likely includes a significant number of deaths that were suicide.
- Non-heart related disease of the major organs (kidney, lung, liver) (total deaths: 53)
- Sudden death in mental illness and epilepsy (total deaths: 24)

Using 2016 as a comparator year we compared our findings to the death data for NSW for 2016 as a whole and found that in some of these categories the people in the unintentional category make up a significant number of deaths overall. When unintentional deaths in NSW in 2016 (n= 251 deaths) are compared to total deaths in NSW in the same year (n= 53,694) the cohort of people in the unintentional

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[1] Definition of 'unintentional'. The 'unintentional' deaths discussed here are unexpected and unintentional, in that they were not reported as being caused by suicide and they were 'unexpected' as the individuals did not have a condition which a medical practitioner asserted that they could have been reasonably expected to die from.

category accounts for 0.4% of all deaths. However, for many of the types of deaths in this cohort the number of deaths is far higher than this percentage. For example:

- Drug-related deaths: 547 state-wide deaths in 2016* but 157 for unintentional and intentional deaths - 29% of drug-related deaths in NSW (discussed further below).
- Pulmonary embolism/ thromboembolism: 139 state-wide but 8 in this cohort – 6%
- Drowning: 68 state-wide but 3 this cohort – 4.4%
- Obesity: 130 state-wide but 11 in this cohort – 8.5%

The deaths that are missing in this cohort are those that may be 'expected' at the time of death. Cancer was an uncommon cause of death in this cohort. Most people with cancer in this cohort actually died from metastatic cancer that had never been diagnosed.

**Drug related deaths**

Over 2012-2016 there were a total of 919 primary drug-related deaths. Of these there were 447 deaths amongst people with serious mental illness who died from unintentional causes (34% of the cohort), and 472 primary intentional drug-related deaths (14% of the cohort). Drugs were also involved as secondary or other causes of death in 420 deaths across both unintentional and intentional categories. Drug-related deaths were increased amongst people aged 25 and under where drug use was a primary factor in 50% of those in the unintentional cohort (n = 24). Aboriginal and Torres Strait Islander people were also more likely to die from a drug-related primary cause, with 43% of deaths overall (n=21) being attributable to a primary drug-related cause.

The large number of drug related deaths in both the unintentional and intentional cohort represents a very high percentage of the total number of deaths by drugs across the NSW population. Over the period 2012-2016 there were 2,647 drug-deaths in NSW for the whole of the population. Over the same period there were 919 deaths amongst those with serious mental illness or who died intentionally. This accounts for 35% of all drug-related deaths in NSW that year.

Prescription or over the counter medications were by far the most common drugs to lead to death in both of the cohorts. Across all years, 66% of unintentional drug-related deaths were primarily caused by over the counter and prescription drug use (without any illegal drug use). A further 21% of unintentional drug-related deaths were primarily caused by both legal and illegal drugs. Only 13% of deaths amongst people who died unintentionally were caused primarily by illegal drugs.

## Questions on Justice

My comments relate to the transition back to the community of people in the Justice system who have significant mental health problems. Currently care for people experiencing mental ill-health transitioning from the criminal justice system is uncoordinated and lacks over-arching policy direction. This results in care that, despite the best efforts of a range of actors is not individualised and recovery-oriented and does not deliver treatment that keeps people safe and well.

Our review of the literature (Smith-Merry et al 2018) shows that effective and structured mental health support during transition back to the community provides protection both in terms of mental health problems and recidivism. Conversely, failure to effectively support people during transition and within the community increases the numbers of people with mental health problems entering and re-entering the criminal justice system.

We recently evaluated a trial transition support program implemented in a Sydney LHD. The findings of that evaluation, introduced below, articulate the difficulties in implementing effective transition in our current system which is poorly organised and does not deal effectively with complexity.

### Summary of the Corrections to Community (C2C) project

The Corrections to Community (C2C) project was a community-derived project which aimed to address the frequent issues encountered by staff attempting to work with people with mental ill-health exiting correctional facilities and transitioning into the community within the Sydney Local Health District. The C2C intervention identified best-practice in transition support and attempted to implement this practice for people with mental ill-health transitioning from the criminal justice system into the Sydney Local Health District (LHD). For C2C participants the following were prioritised: in-reach where contact is made by community mental health prior to release, stable accommodation, that the individual has a GP, the individual is seen by community mental health within seven days of release and if an individual moves out of catchment referral is made to services in new region. Inclusion in Partners in Recovery (PIR) was also prioritised for all participants. Fourteen individuals were included in the C2C intervention.

The research component of the C2C study was carried out by the Centre for Disability Research and Policy within the Faculty of Health Sciences at the University of Sydney. The research involved three phases:

1. a systematic review of literature on recovery-oriented transition services for people exiting criminal justice settings
2. an analysis of aggregated data collected on C2C participants at release, seven days post release and 28 days post release.
3. qualitative interviews with key stakeholders to understand the existing barriers and facilitators of effective transition from custody to the community.

### C2C participants: aggregated data.

The data on the C2C participants showed that individuals released into Sydney LHD came from a very broad range of correctional facilities. Notification of future release to Sydney LHD took place an average of 27 days before release. Despite prioritisation of in-reach and a long lead-time before release in-reach only occurred for three of the 14 participants. Individuals at release had very variable relationships with family and friends and most were released into unstable accommodation. Only four remained in the same accommodation from release to the 28 day follow up.

At the end of the C2C data collection period at 28 days half of the clients where engagement had been attempted were still engaged with the program. For those who had disengaged this was due to two main factors: 1) drug problems (which led to disengagement or reincarceration) and 2) accommodation changes which saw them move out of catchment. For most of the clients accommodation was very unstable. Of those clients who remained engaged after seven days all were well engaged with mental health services.

### Results from interviews with key stakeholders.

The qualitative interviews with key stakeholders in Justice Health, Sydney Local Health District Community Mental Health and Inner West Partners in Recovery revealed a range of pressing service and consumer-related factors which hampered effective transition.

Service related factors included poor communication, a lack of understanding between organisations, poor information sharing systems and unstable connections based on individuals rather than system roles. Interview participants also emphasised the importance of in-reach and through-care (where the community mental health team or other service continues to meet with someone while they are incarcerated) but a lack of support for accomplishing this. Staff also reported that consumers are released through the courts without any individuals involved in their care being informed, including Justice Health nurses, PIR and the community mental health team. This increases the likelihood of the consumer being lost to care.

Consumer-related factors related to unstable accommodation and consumer preoccupation with the immediate needs of housing and subsistence upon release which forces a deprioritisation of engagement with mental health supports. Consumers also had additional problems such as substance misuse and intellectual disability that impacts on their engagement with services. Engaging consumers once in the community is often very hard and requires long-term persistence and management of risky behaviours.

Participants did not point to any existing effective system-wide or local programs which were currently addressing the system or consumer-related factors that were raised.

A very significant problem was individuals exciting the program into unstable accommodation and then exiting the LHD area, which meant that the LHD could no longer include them in programs. This is an example of the poor adaptability of current systems which are unable to visualise care from the individual's perspective, and instead prioritise care based on LHD boundaries.

**Recommendations for reform.**

While the data identifies many points of action we made six key recommendations about reform which if implemented will serve to develop a better integrated system resulting in more effective outcomes for those people with mental ill-health transitioning from correctional facilities.

1. **Development of a shared information system.**
2. **Creation of a state-wide forensic care community.**
3. **Active development of local communities of practice.**
4. **Development of an accommodation strategy for former inmates with mental ill-health.**
5. **In-reach and through-care as standard practice.**
6. **Court hand-over when an individual is released directly from a court hearing.**

These recommendations are explained in further detail in the full version of the report which is available on request.

Essential to reform is a strong policy prioritisation. This is because these recommendations can only be implemented through a multi-agency approach. We call for action on these issues by high level actors including the New South Wales Mental Health Commission, the NSW Government, Justice Health and Corrections NSW.

The project has also been published in two journal articles:

1. Smith-Merry, J., Mellifont, D., McKenzie, K, Clenahagn, P. (2018, forthcoming) A narrative review of mental health support for people during transition from incarceration to community: The Grass Can Be Greener on the other Side of the Fence. *Journal of Mental Health.* 28(2):189-197.
2. Hancock, N. Smith-Merry, J. McKenzie, K. (2018) Facilitating people living with severe and persistent mental illness to transition from prison to community: A qualitative exploration of staff experiences. *International Journal of Mental Health Systems*, 12(1), 45

## Questions on service gaps – particularly relating to the NDIS

The NDIS is necessarily a scheme which has firm boundaries around what it supports and how much it will support an individual. These boundaries are difficult to shift and this causes problems for people with mental illness (termed psycho-social disability within the NDIS) whose illness may be characterised by periods of acute ill-health, stability and recovery. People also have needs that cross boundaries of service systems and involve high-level collaboration between these systems for their needs to be served (e.g. health, housing, education, the NDIS). This complexity is very difficult to manage through the NDIS itself, because of those strict boundaries referred to above.

State and territory governments are now introducing programs to attempt to address this complexity and to bring about more connected systems, however these programs currently lack ongoing funding. An example is the Integrated Service Response program being trialled in NSW and (with some differences) in the ACT.

In 2018 we published the report *Mind the Gap: The National Disability Insurance Scheme and Psycho-social Disability*. This report was moved and passed as a motion for noting in the Federal Senate and has received widespread media attention because it drew attention to significant gaps related to the provision of support for psycho-social disability both within the NDIS and for those who were not eligible but needed ongoing support. Please refer to that report for an in-depth discussion of those issues.

## Questions on education, training and employment

The responses in this section relate to preliminary findings from a major study being conducted called Disability, Disadvantage and Vocational Education and Training (VET) which examines the current barriers to people with disability (specifically including mental illness) accessing and completing VET and transitioning to employment. This study is funded by the NSW Department of Industry over 2018-2019. The first major output of this project has been an in-depth systematic literature review which, though focusing on disadvantage in general, included a strong focus on mental health as one of the major disability groups. Specific mental health related findings from that literature and more general findings on disability which are relevant to mental illness are included here.

### Disclosure

In the current VET system disclosure of disability, including mental illness, is important because it allows funding to be allocated to providers who can then use that funding to provide specialised services. However, the findings from the literature review show that there is a general reluctance to disclose when students are enrolling in VET. This is because of perceived stigma and poor past experiences such as receiving inadequate support. This was particularly a problem for disabilities that are highly stigmatised, with people experiencing mental ill-health most disinclined to disclose disability. Staff found lack of disclosure to be frustrating because they could not provide services to assist them. Solutions articulated in the literature relate to a generalisation of supports and culture change in organisations.

### Individualisation

Individualised programs of support make course completion and successful transition to employment more likely. Individualisation occurs when supports are focused on the individual in the context of their lives, rather than services developing models that offer supports based on categories of disadvantage or diagnoses. Individualisation relies on a number of key practices:

- Genuine dialogue with individuals to really understand what supports they need and the extent to which they can be offered in a particular organisational environment.
- An understanding of an individual's strengths so that they can be prioritised to avoid a 'deficit' model where individuals are only seen in relation to their mental illness.

- Integration of support from an individual's existing service supports so that there is a seamless transition between the different aspects of an individual's life and support (see collaboration, below).

While individualisation is possible without disclosure it becomes easier when mental illness is disclosed as it allows conversations to occur early so that planning can take place. Individualisation can occur without disclosure where it becomes something that applies to all students.

**Collaboration**
Cross-sector collaboration in this context refers to services and sectors working together to ensure an individual progresses through VET and into employment. There are several positive benefits to this. For the individual cross-sector collaboration means that individuals receive consistency of supports that wrap around a person rather than being confined to a single sector and leaving the individual to negotiate between sectors. In practice this would mean mental health services who are already supporting an individual being involved in appropriate ways in classroom teaching, work placement or in the transition to employment. It would also involve dialogue between VET staff and employers around an individual's needs prior to commencing employment and as part of the transition. This increases rates of course completion because it means that impacts from mental illness on study and employment become less acute. For staff working within services, clear dialogue between sectors leads to increased familiarity and enhances understanding of VET: services better understand the employment and education context of the people that they work with.

To facilitate collaboration there needs to be incentives built in to existing funding arrangements which mean that funding becomes dependent on considerations of joint practice (e.g. shared meetings, individualised plans which identify and create dialogue between relevant services). This individualised approach is supported by more generalised processes which create ongoing dialogue between relevant sectors. This may be facilitated by funding to create localised networks of individual support organisations, VET organisations and employers. Individualised approaches around specific groups of students are also effective.

**Mental health literacy, confidence and knowledge**
Poor mental health literacy and confidence amongst VET staff and employers is a significant barrier for cultures of inclusion and employer commitment to employing people with mental illness. This in turn impacts on multiple aspects of an individual's experience of both VET and employment. Poor knowledge about mental illness is the key factor driving low confidence levels. Low levels of confidence was viewed as particularly problematic for emerging and small providers, or for employers of small businesses. This is because those organisations lack a broad range of staff or a long history from which to learn about employment and training of people with disability, including mental illness.

Poor knowledge or confidence manifests in the following practices/problems:

- Employers underestimating the skills of people with mental illness
- Employers overestimating the expense related to accommodations for mental illness
- VET staff overestimating the time and resources needed to assist students, or the supports that they can access themselves to do so.
- VET staff have poor knowledge about how to create inclusive materials or create an inclusive culture in the classroom.

Poor knowledge also leads to the perpetuation of stigma and to students feeling that they are unsupported.

Addressing poor disability knowledge can take place through activities designed to increase disability awareness. Steps are:

- Mandatory training in mental illness for all VET staff
- Development of a disability focused organisational culture (including mental illness)

- Collaboration around ideas and approaches between VET staff and other services (also discussed above).

One of the biggest blocks identified in the literature was about the transition process for people exiting VET and moving into employment. At the heart of these blocks was poor disability knowledge and confidence (discussed above) and poor knowledge of supports that are available to employers. Because it is not possible to mandate either employer training or inclusion of people with disability, other strategies to encourage inclusion were needed. The following effective strategies were identified:

1. Creation of a competitive market where employers find it desirable to focus on diversity and inclusion and compete on these terms. This strategy would need to be facilitated by the government or industry groups.
2. Awards or certification levels for disability-related employment which focus on incremental changes to encourage the development of inclusive cultures.
3. Financial incentives:
    - "Ice-breaker" wages for people with disability who are newly graduated
    - subsidised wages for employees who need to work flexibly

However, incentives are only shown to be effective when there was good understanding of mental illness by employers.

A full copy of this literature review is available on request. This links the points made here, with specific studies.

## About the Centre for Disability Research and Policy

The Centre for Disability Research and Policy (CDRP) at the Faculty of Health Sciences of the University of Sydney aims to change the disadvantage that occurs for people with disabilities. We do this through addressing their social and economic participation in society, and their health and wellbeing. By focusing on data that demonstrates disadvantage, we can develop models of policy and practice to better enable support and opportunity for people with disabilities.

## About Associate Professor Jennifer Smith-Merry

Dr Jennifer Smith-Merry is Associate Professor in the Faculty of Health Sciences at the University of Sydney. Jen is Director of the Centre for Disability Research and Policy (CDRP). The CDRP is a multi-disciplinary centre whose mission is to make life better for people with disability in Australia and our region by developing research and translating this to policy and practice through involvement in partnerships and policy development. Her academic research has focused on policy and service development, primarily in mental health and the study of adverse events. Prior to her current position she was Research Fellow at the University of Edinburgh. Jen is lead Chief Investigator on multiple grants which aim to evaluate or develop policy and services in disability and mental health. She works closely with people with a lived experience of disability and has a strong interest in the value of lived experience in informing policy and service design.

Jen has strong connections to academic, policy and service audiences in Australia and internationally. She has published over 60 peer-reviewed articles and book chapters. Jen recently led the development of the *Mind the Gap* report into the National Disability Insurance Scheme (NDIS) and psychosocial disability. This report drew attention to the significant problems faced in delivering NDIS in the context of mental health. The report was passed as a motion in the Federal Senate and received significant media and policy attention.