

Submission to the Productivity Commission for its Mental Health Draft Report

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There is much to commend in the Productivity Commission Draft Report ('Draft Report'). This submission will focus on three areas that we believe would strengthen the report. These are:

- (1) access to income support for people with mental health conditions or psychosocial disabilities and their carers and supporters;
- (2) new and emerging digital technologies in mental health services; and
- (3) coercive practices in mental healthcare.

We will address each in turn.

Income support for consumers and carers

The Draft Report highlights the significant shortcomings of the income support system for mental health consumers and people with psychosocial disabilities, and their carers and supporters. We welcome the Productivity Commission's ('PC') attention to a range of problematic aspects of the current system and recommendations for improvement, including expanding access to Carer Payment to those with 'regular' but not necessarily 'constant' responsibilities; giving carers greater scope to participate in paid work or volunteering by moving from a 25-hours-per-week test to a more flexible 100-hours-per-month test; reviewing the test used to measure carers' care responsibilities to better capture the nature of caring for someone with a mental health condition; and improving the assessments currently used to determine the level and nature of employment support for people with disability claiming Newstart Allowance.

We note the PC's focus on supporting the employment of people with mental health conditions or psychosocial disabilities and their carers and supporters. This is undoubtedly important in light of the discrimination and other barriers that often impede workforce participation. However, we urge the Commission to also directly address the risks of financial hardship and poverty associated with inadequate income support for these groups.

The Draft Report describes income support as 'an important safety net' and suggests that many mental health consumers and people with psychosocial disabilities, and their carers and supporters, are falling through that net because they cannot access adequate income and employment support. This creates real risks of poverty and hardship. In this regard, we draw the PC's attention to recent NATSEM research commissioned by the Australian Federation of Disability Organisations. The report demonstrates that households with a member with disability claiming either Disability Support Pension or Newstart are much more likely to experience financial hardship and insecurity than Australian households generally.² The researchers calculated the 'cost of disability' – meaning the amount necessary for households with an adult member with a 'profound or severe' disability to achieve the same standard of living as households that do not have an adult member with a disability – to be \$173 per week on average above the household's 2015-16 income, and up to \$489 for some household types.³ Two policy options that might more adequately account for this 'cost of disability' through the income support system were modelled, namely, increasing the rate of payment for Disability Support Pension and expanding access to the payment to a broader range of claimants. Carers' advocacy organisations have expressed their concerns about the implications of these findings for all members of households,⁴ and raised other concerns about the availability and adequacy of Carer Payment in submissions to the present PC inquiry.

We note with concern that the PC did not recommend a change to, or review of, the rate at which Disability Support Pension or Carer Payment are paid. Likewise, the PC noted the submissions it had received about the inadequacy of the rate of Newstart Allowance but declined to recommend that this be addressed directly, on the basis that it is not specific to people with mental health conditions. In our view, better support for employment must be accompanied by real social protection for those who cannot attain an adequate standard of living through paid employment due to impairment, disability, care and support responsibilities, or some combination of these factors. It also requires direct attention on some of the fundamentals of the income support system, drawing on the growing evidence of the ineffectiveness and harms arising from the imposition of compulsory participation requirements on many income support recipients, including many people with mental health conditions or psychosocial disabilities.⁵ the failure of

the 'jobactive' program to effectively support people into work, and the inappropriateness of the mainstream Newstart and jobactive systems for many people with disabilities. While we acknowledge that this may be outside the scope of the inquiry, the inquiry arguably presents an opportunity to gather evidence of the specific or unique impacts of these matters on people with mental health conditions or psychosocial disabilities and their carers and supporters, especially in light of the growing proportion of people claiming income support on the basis of a 'psychological/psychiatric' condition.⁷

Recommendations

- Explore the impacts and consequences of the current rates of payment for Disability Support Pension, Carer Payment, Newstart Allowance and other income support payments on people with mental health conditions or psychosocial disabilities and their carers and supporters.
- Consider making recommendations that directly address the sufficiency of income support for people with mental health conditions or psychosocial disabilities and their carers and supporters.

Digital Technology in Mental Healthcare

As the PC identified, new and emerging digital technologies bring opportunities and risks for mental healthcare. The report strongly emphasises the positive potential for using digital technologies, including to break down geographical barriers and provide effective treatment, care and support to consumers, particularly in rural and regional areas. In terms of risks, the report reflects broad agreement that online interventions should *augment* rather than *replace* face-to-face support – a conclusion we support – and the recommendations reflect this. There are other potential risks that may not have been considered, which we urge the PC to consider. These include:

- implementation and regulation being affected by insufficient integration and failure of technologies to be adaptable to real-world complexity;
- algorithmic bias and discrimination in the use of machine learning:
- the excessive medicalisation of distress through digital platforms; and
- the challenges of achieving free and informed consent in the digital context, and so on.8

However, we will focus on three points for the purposes of this presentation: first, the paucity of supportive research for the efficacy of digital mental health technologies; second, the issue of data security; and third, the importance of deliberative, consumer-engaged development and implementation.

The evidence-base for the effectiveness of various digital mental health technologies is sparse. As a general observation, research on digital technology in the mental health context often lacks generalisable results, is rarely subject to repeated studies, there are few RCTs, and there remain many small-scale studies with differing results. Regarding app-based mental health intervention, for example, Simon Leigh and Steve Flatt characterise the range of mental health apps as suffering from a 'frequent lack of an underlying evidence base, a lack of scientific credibility and subsequent limited clinical effectiveness'. According to another systematic search by Amit Baumel and colleagues, only 4% of mental health users continue using mental health apps after two weeks, and 'continued use'

is measured merely by opening the app.¹⁰ It is true that evidence for other practices using digital technology does look promising – for example, in some types of internet-based counselling options, as the Draft Report rightly highlights. Nevertheless, there remain risks associated with overhyping technology without a commensurate evidence base. Despite the PC draft recommendation that digital interventions should be subject to small-scale testing before they are scaled-up, there are some occasions where the evidence is potentially over-stated in the Draft Report. On page 265, for example, the authors note that:

"Based on clinical evidence, older adults can obtain large and clinically-significant benefits from supported online treatment (Titov et al. 2015b)."

Yet in the paper by that is cited, Titov and colleagues are more circumspect, stating that:

The results support the *potential* efficacy and cost-effectiveness of therapist-guided iCBT as a treatment for older adults with symptoms of depression.¹¹ (Emphasis added)

The risk of over-hyping technology has implications on both the individual and population-level, ranging from shaping individual patient and service users' preferences and expectations about treatment, to altering how funding is directed. There must be robust evidentiary standards before online services are introduced.

Data security is another major risk, warranting careful consideration by the PC. The literature suggests that the personal data gathered by digital mental health technologies are typically haphazardly protected and insufficiently regulated for which the amount and nature of the collection is unclear. Privacy laws, which underpin most of the relevant regulatory schemes, were generally written prior to the explosion in the digital health market and the era of 'big data', and may not provide robust protection for consumers' sensitive personal information. Data theft will become increasingly prevalent, as was the case in the US in 2017, when a mental health service provider in Texas notified 28,434 patients whose data was allegedly stolen by a former employee. Without robust protections, there is a risk that poor consumer-trust can have negative flow-on effects for mental health service use, which may serve as yet another barrier to people in mental health crises accessing preventive support. According to the Consumer Policy Resource Centre:

consumers may well start to avoid accessing important healthcare services and support if they feel that companies or governments cannot be trusted with that information, or that they may be disadvantaged by that information in future. For example, insurer MLC was found to have excluded a consumer from mental health coverage in life insurance due to her accessing mental health services for the sexual abuse she suffered as a child in the mid-1980s. Location tracking (in a 5G environment) in particular may provide insights into the frequency and types of healthcare services that an individual might be accessing, regardless of whether formal medical records are being accessed.¹⁵

Data security concerns should not create an additional barrier for Australians who may wish to access mental health services. Past failures must inform any cost-benefit analysis of a proposal to digitise parts of the mental health services of Australia. In 2015, for example, the National Health Service ('NHS') England was forced to close its App Library after a study found that 28 per cent of apps lacked a privacy policy and one app even transmitted personal identifiable data that its policy claimed would be anonymous.¹⁶ Any cost-benefit analysis must account for the fact

that digital technologies can increase the susceptibility of individuals and communities to harms to health and safety, including decreased privacy, third party organisations leveraging information against users' interests, reputational injury, discrimination, and so on. Proponents of digital mental health technologies need to go beyond vague notions of 'privacy' or 'innovation' to address broader social consequences of such health information collection, aggregation, and use.

From a pragmatic perspective, the involvement of service users and people with psychosocial disabilities is generally agreed to increase the likelihood of 'viable and effective—rather than disruptive and short-lived—advances' in digital technologies in the mental health context. Thoughtful, deliberative design is likely to result in higher quality technologies that better meet the needs and preferences of those for whom the technologies are designed. According to Rishi Duggal and colleagues, a robust regulatory framework will only emerge when service users, patients, persons with disabilities, clinicians, and providers collaborate to design a 'forward thinking, future proof, and credible regulatory framework that can be trusted by all parties'. Without it, there is a greater likelihood of costly technologies being introduced in an unthinking and costly manner, created to address one issue without sufficient thought to harmful flow-on consequences. To ensure greater equity in design, development and regulation, there is a need for 'interdisciplinary empirical research on the implications of these technologies that centers the experiences and knowledge of those who will be most affected'. Service users, service providers, family members and other relevant groups, must be able to exert control over how and to what extent their services are digitised. The integration of digital technology into some of the most vulnerable aspects of people's lives must be accompanied by means to contest, account, and give redress to citizens and representatives of the public interest.

Despite the concerns raised above, again, we acknowledge the positive potential of digital technology to improve the quality and safety of services for people with mental health conditions and psychosocial disability. Indeed, other positive examples, which were not discussed in the Draft Report, include **facilitating** '**supported decision-making**', in line with mental health policy priorities in some States and Territories, and in the Australian Law Reform Commissions 'National Decision-making Principles'.²⁰ The CommonGround computer-interface for mental health services is a good example of technology that promotes supported decision-making, in ways that are developed and facilitated by peer workers. CommonGround was developed by a prominent consumer advocate in the US.²¹ The computer interface is presented to people on arrival to mental health services, and service users are assisted by peer workers to complete a pre-consultation report about their personal preferences and values before meeting with a medical professional.

Another area in which digital technology can improve outcomes is in **preventive monitoring and the gathering of vital statistics** with the aim of preventing violence and abuse against persons with disabilities, including mental health consumers. An example of this is the use of machine learning to detect excessive prescription rates for psychotropic medication in aged care facilities in New South Wales.²² Lisa Pont and colleagues, for example, used new information technology to monitor medicine use in 71 residential aged care facilities in Australia, with the aim of identifying systemic problems, such as prescribing errors and medication misuse. National data registers could be oriented toward this type of digitised monitoring—not of service users, but of service providers. One major aim of the study by Pont and colleagues was to address the serious human rights concern raised by excessive prescription of psychiatric pharmaceuticals, particularly to older persons. The authors' digital initiative used routinely collected date

to alert regulators to high rates of psychotropic medication-use in some facilities that could not be easily explained, flagging the need for further checks. From a regulatory perspective, these findings suggest that it may be more effective to prioritise the quality and accessibility of the data in electronic systems over investing in stand-alone, resource-intensive auditing processes.

Recommendations

- Clearly identify risks with various forms of digitisation of mental healthcare, including patchy evidence and data security.
- Emphasise the need for robust evidentiary standards applied to online mental healthcare initiatives, akin to matters considered by the Therapeutics Goods Association.
- Recommend the involvement of mental health consumers in developing and implementing digital service initiatives, including in regulatory efforts.
- Note the benefits of consumer-led technologies in supporting decision-making in the mental health context, and the use of digital technologies in the preventive monitoring of abuse, neglect and other rights-violations in mental health and other services.

Involuntary Treatment

The Draft Report contains no analysis of the use of compulsory treatment or coercion in mental health services and its associated costs. 'Coercion' refers here to restrictive practices such as compulsory treatment in hospital and community, involuntary admission and other deprivations of liberty in hospitals, restrictive practices like seclusion and restraint, and so on. Formal coercion typically occurs in acute mental health services, which are managed by State and Territory governments. We assume, therefore, that this topic was seen to fall outside the federal remit of the inquiry. However, we submit that coercion in mental health services falls within the scope of the inquiry in several ways.

First, the federally-funded National Mental Health Commission has called for the reduction of involuntary hospital admissions and use of restrictive practices, including in its Fifth National Mental Health and Suicide Prevention Plan ('National Plan'). The National Plan states that a 'well-integrated, effective and sustainable mental health service system for people with severe and complex illness will be reflected by':

reduced need for involuntary hospital admission (PI 23) and reduced use of restrictive practices such as seclusion (PI 22). (emphasis added)

The National Mental Health Commission also 'supports working towards the elimination of seclusion and restraint of people experiencing mental health difficulties in mental health services', as evident in its 2015 statement on seclusion and restraint and the accompanying materials.²³

Second, coercion is a key feature of Australian mental health services and given its scale, creating flow-on effects to primary mental health services. The Australian Institute of Health and Welfare ('AIHW') highlight the pervasiveness of coercion:

- 45.8% overnight mental health-related hospital separations with specialised psychiatric care were for people with an involuntary legal status in 2017–18.²⁴ In some states the rate is higher, as in Victoria, where the rate was 52 per cent.²⁵
- Nationally, around one in five residential mental health care episodes (**20.0%**) and **one in seven** community mental health care service contacts (**14.5%**) were also involuntary in 2017-18.²⁶
- There were approximately **1,340,130** community mental health care service contacts for people under an involuntary status in 2017-18.²⁷ Federally-funded services are particularly likely to play a significant role in compulsory community treatment, as discussed below.
- There were **11,315 seclusion events** reported nationally in public sector acute mental health hospital services in 2017-18.²⁸
- There were **16,917 physical restraint events, and 796 mechanical restraint events**, reported nationally in 2016-17.²⁹

It seems highly unlikely, if not impossible, that the figures above do not implicate federally-funded and managed mental health services—whether directly in the provision of services, or indirectly in terms of the flow-on effects of coercion for primary care services.

Despite this significance, the 110+ pages of the *Overview and Recommendations* section of the Draft Report contain no reference to 'compulsory treatment' or 'restrictive practices'. Nor do the terms 'seclusion' and 'restraint' appear in this concluding part of the report. 'Restraint' appears just once in *Part 1* (where it appears indirectly among a list of purported benefits of a proposed ED program) and four times in *Part 2* (where it appears in passing reference to an existing dataset on seclusion and restraint). 'Seclusion', which neither appears in *Part 1* nor the *Overview* at all, appears in *Part 2*, again, simply with reference to existing datasets.

The term 'community treatment order' does not appear at all in the report, and no reference is made to compulsory community treatment more generally. This is particularly striking given compulsory community-based treatment is a prominent part of mental health service provision across Australia, as noted in the AIHW statistics above. Australia has some of the highest rates of compulsory community treatment in the world, 30 and its use remains controversial. 31 Community treatment orders have been subject to strong criticism by prominent researchers, 32 and raise serious human rights concerns, as evident in specific criticism of Australia's compulsory community treatment practices by the United Nations Committee on the Rights of Persons with Disabilities. 33 Edwina Light and colleagues found that clinicians held the perspective that forced community treatment was used to signify a need for priority access to care in a service system that may not respond adequately to those engaging voluntarily. 34 Gilles Newton-Howe and Christopher Ryan have argued that limiting human rights to remedy service system failures is 'Kafkaesque'. 35 We strongly urge the PC to engage with the extensive service data and research material on community treatment orders in Australia in order to scrutinise this major component of national mental health services.

All forms of coercion exert significant social and financial costs. These costs – and any benefits – must be counted in any enumeration of Australia's mental health system. Most clinicians consider coercion to be a necessary last resort, but it is also generally acknowledged that individuals subject to coercion are susceptible to harms that include physical pain, injury and even death. People who have experienced coercion first-hand in mental health services, as

well as their family members and supporters, have drawn attention to some of the harms of those practices through testimony and advocacy.³⁶ The use of coercive measures can be traumatising and, in relation to the aims of mental health services, may harm individual recovery, undermine therapeutic relationships and repel service users from seeking help in the future. Coercion may also damage staff morale, and traumatise other service users and staff members.³⁷

Dr Gooding has argued that 'support re-investment' could provide a policy principle for moving resources currently used for coercion to voluntary support.³⁸ Costs associated with compulsory community treatment, for example, currently include clinical administration and delivery, monitoring and regulation by mental health tribunals, as well as the resources needed for ordering people to hospital. This includes multiple emergency services, such as police, ambulance, and emergency departments, as well as primary care providers.

Gooding and colleagues have also produced a review of the research on alternatives to compulsory treatment and other coercive practices to date.³⁹ The research suggests that efforts to reduce, prevent and end coercion appear effective in most empirical studies that have taken place. Several promising leads have not been further evaluated by services, governments, and others. To take one Australian example, consider Bradley Foxlewin's study, commissioned by the Australian Capital Territory (ACT) Mental Health Consumer Network.⁴⁰ Foxlewin's project examined seclusion reduction interventions at a single hospital in the ACT, in which seclusion incident rates reportedly fell from 6.9% in 2008/9 to less than 1% in 2010/11.⁴¹ Further, many of the successful policy and programming options represent low cost, or 'no cost' initiatives, and could be developed through the redistribution of existing resources. The wider body of research suggests that a broad suite of practices, policies and interventions exist, which can be implemented at local, state and territory, and national levels. A policy 'charter' or 'framework' could collate these findings, outlining the broad package of alternatives that have been introduced and tested elsewhere, or which warrant further investigation.

The gaps in the Draft Report concerning coercion and restrictive practices are particularly striking given the high level of activity on these topics in the mental health sector in recent years, including among consumer and disability organisations,⁴² including inquiries responding to specific instances of harm from restrictive practices,⁴³ and the extensive 'restrictive practice' database of the AIHW. We urge the PC to engage with this pressing topic in its Final Report.

Recommendations:

- Characterise coercion as a core part of existing hospital and community-based mental health services in Australia, and examine its relationship to federally-funded services.
- Subject coercion in its various forms to robust evidentiary standards concerning its efficacy, impact (including flow-on to primary services), and so on.
- Analyse coercive practices, including the social and financial consequences of compulsory hospital treatment, hospital detention, compulsory community treatment, seclusion, restraint, and so on.
- Explore the social and financial benefits (and potential costs) of reducing coercive practices, with a view to elimination.

• Explore ways to collect consistent data within and between states and territories regarding the use of coercion, with a view to promoting reduction and elimination.

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- ² Jinjing Li, Laurie Brown, Hai Anh La, Riyana Miranti and Yogi Vidyattama. *Inequalities in Standards of Living: Evidence for Improved Income Support for People with Disability*. Report prepared for the Australian Federation of Disability Organisations. NATSEM, University of Canberra 2019. https://www.afdo.org.au/wp-content/uploads/2019/09/02A-NATSEM-Online-Disability-Report.pdf

 ³ Ibid, 22.
- ⁴ Carers Australia, 'Disturbing Gap between the Disability Support Pension and Cost of Living for People with Disabilities' Media Release. 18 September 2019. https://www.carersaustralia.com.au/media-centre/carers-national-news/article/?id=disturbing-gap-between-the-disability-support-pension-and-cost-of-living-for-people-with-disabilities
- ⁵ Mental Health Council of Australia, *Key Issues Brief: Mental Illness and the Income Support System*. nd. https://mhaustralia.org/sites/default/files/docs/mental illness and the income support system key issues paper.pdf
- ⁶ See for example, Senate Education and Employment References Committee, *Jobactive: Failing Those it is Intended to Serve*. Commonwealth of Australia 2019.
- ⁷ Samuel B Harvey, Mark Deady, Min-Jung Wang, Arnstein Mykeltun, Peter Butterworth, Helen Christensen, Philip B Mitchell (2017) 'Is the Prevalence of Mental Illness Increasing in Australia? Evidence from National Health Surveys and Administrative Data', 206(11) *Medical Journal of Australia* 490-493.
- ⁸ I have discussed some of these issues elsewhere. P Gooding, 'Mapping the rise of digital mental health technologies: Emerging issues for law and society' *International Journal of Law and Psychiatry* (2019) 67.
- 9 Simon Leigh and Steve Flatt, 'App-Based Psychological Interventions: Friend or Foe?' (2015) 18(4) Evidence-Based Mental Health 97, 97.
- ¹⁰ Amit Baumel et al, 'Objective User Engagement With Mental Health Apps: Systematic Search and Panel-Based Usage Analysis' (2019) 21(9) *Journal of Medical Internet Research* e14567.
- ¹¹ Nickolai Titov et al, 'Clinical and Cost-Effectiveness of Therapist-Guided Internet-Delivered Cognitive Behavior Therapy for Older Adults with Symptoms of Depression: A Randomized Controlled Trial' (2015) 46(2) *Behavior Therapy* 193, 193.
- ¹² See generally, Piers Gooding, 'Mapping the Rise of Digital Mental Health Technologies: Emerging Issues for Law and Society' (2019) 67 *International Journal of Law and Psychiatry* (online first).
- ¹³ Mark Erik Larsen et al, 'Using Science to Sell Apps: Evaluation of Mental Health App Store Quality Claims' (2019) 2(1) npj Digital Medicine 1 ('Using Science to Sell Apps').
- ¹⁴ HIPAA. (2017, December 5). PHI of 28,000 Mental Health Patients Allegedly Stolen by Healthcare Employee. *HIPAA Journal*. Retrieved from https://www.hipaajournal.com/phi-28000-mental-health-patients-stolen-by-healthcare-employee/
- ¹⁵ Brigid Richmond, 'A Day in the Life of Data: Removing the opacity surrounding the data collection, sharing and use environment in Australia', Consumer Policy Research Centre (2019) https://cprc.org.au/wp-content/uploads/CPRC-Research-Report A-Day-in-the-Life-of-Data final-full-report.pdf.
- ¹⁶ Paul Wicks and Emil Chiauzzi, ""Trust but Verify" Five Approaches to Ensure Safe Medical Apps' (2015) 13(1) *BMC Medicine* http://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-015-0451-z.
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- ²⁰ Australian Law Reform Commission. <a href="https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/3-national-decision-making-principles-2/nation-making-principles-2/nation-making-principles-2
- ²¹ Pat Deegan, 'A web application to support recovery and shared decision making in psychiatric medication clinics' (2010) 34 *Psychiatric Rehabilitation Journal* 23–28.
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- ²⁴ AIHW, *Mental health services in Australia: Web report* Last updated: 09 Oct 2019 https://www.aihw.gov.au/reports/mental-health-services/mental-health-services/mental-health-services/mental-health-services-in-australia/report-contents/restrictive-practices-.
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- 32 See above, n 31.

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 ³⁴ Light et al, above n 30.
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- ⁴² For example, Restrictive Practice Working Group, *National Principles to Support the Goal of Eliminating Mechanical and Physical Restraint in Mental Health Services*. Australian Health Ministers' Advisory Council, 15 December 2016; National Mental Health Commission, *A Case for Change: Position Paper on Seclusion, Restraint and Restrictive Practices in Mental Health Services*. Australian Government 2015;
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