



#### WITNESS STATEMENT OF DR PIERS GOODING

I, Dr Piers Gooding, Research Fellow at the Melbourne Social Equity Institute and the University of Melbourne Law School, of 201 Grattan Street, Carlton, Victoria, say as follows:

#### Background

- I make this statement on the basis of my own knowledge, save where otherwise stated.

  Where I make statements based on information provided by others, I believe such information to be true.
- I am providing evidence to the Royal Commission into Victoria's Mental Health System in my personal capacity.

### Overview of my experience

- I am a Research Fellow at the Melbourne Social Equity Institute and the University of Melbourne Law School. I have been based at the Institute for the past five years. My work focuses on mental health law, policy and practice. I have a particular interest in mental health legislation, and the policy and social context in which it operates. I have also worked on issues of mental health and criminal law, as it relates to legal capacity and access to justice for persons with disabilities. In more recent years, my work has explored the legal and policy implications of digital technology used in mental health care.
- My research has also focused on international human rights law related to mental health and disability. For example, I recently undertook a study for the United Nations ('UN') Special Rapporteur on the Rights of Persons with Disabilities, and later the World Psychiatric Association, on efforts to reduce coercive or compulsory practices in mental health services.<sup>1</sup>
- In 2017, I wrote a book called 'A New Era for Mental Health Law and Policy: Supported Decision-Making and the UN Convention on the Rights of Persons with Disabilities' (2017) with Cambridge University Press. Since 2015, I have been on the editorial board of the International Journal for Mental Health and Capacity Law.

Please note that the information presented in this witness statement responds to matters requested by the Royal Commission.
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<sup>&</sup>lt;sup>1</sup> P Gooding, B McSherry and C Roper, 'Preventing and Reducing "Coercion" in Mental Health Services: An International Scoping Review of English-Language Studies' (2020) *Acta Psychiatrica Scandinavica* (online first); P Gooding, B McSherry, C Roper and F Grey, (2018) *Alternatives to Coercion in Mental Health Settings: A Literature Review*, Melbourne: Melbourne Social Equity Institute, University of Melbourne.

- I have worked with a range of international organisations and agencies, including the UN Special Rapporteur for the Rights of Persons with Disabilities, the UN Special Rapporteur on the Right to Health, and as a consultant to the UN Economic and Social Commission of the Asia Pacific.
- Between 2014 and 2015, I was a research fellow at the Centre for Disability Law and Policy at the National University of Ireland, Galway. Prior to working in academia, between 2008 and 2010, I was a research officer at Tandem the peak Victorian mental health carer organisation. Between 2011 and 2015, I was also volunteer Community Visitor with the Office of the Public Advocate, a role in which I made monthly visits to closed mental health settings in Melbourne.
- I hold a Bachelor of Arts (with First Class Honours) from the University of Melbourne and a PhD in Law from Monash University. My thesis topic concerned supported decision-making, the Convention on the Rights of Persons with Disabilities, and mental health legislation.
- 9 Attached to this statement and marked "Attachment PG-1" is a copy of my curriculum vitae.

#### My current role and responsibilities with the Melbourne Social Equity Institute.

- In my current role as Research Fellow at the Melbourne Social Equity Institute, I undertake socio-legal research on mental health law and policy, and broader disability law and policy. My research fits into one of the Institute's major focus areas—'mental health and society'.
- I have a minor teaching role, co-ordinating a Doctoral Academy of PhD students across the University engaged in inter-disciplinary research into matters of social equity. In late 2019, I was a co-ordinator for the Disability Human Rights Clinic at the Melbourne Law School. In 2020, I am a contributing lecturer to a student law clinic for NDIS participants.
- I was recently awarded a Discovery Early Career Research Award from the Australian Research Council to look at law and policy concerning digital technologies used in mental health care, which I will focus on over the next three to four years.
- In July 2019, together with my colleagues at the Institute, I helped prepare a submission to the Royal Commission which discussed the use of compulsory treatment in Victoria's mental health system.<sup>2</sup>

<sup>&</sup>lt;sup>2</sup> P Gooding and Y Maker, 'Submission to The Victorian Royal Commission into Mental Health', July 2019.

#### **Future digital opportunities**

#### The impact of the digital revolution on the mental health of Victorians

Victorians are deeply affected by the changes brought by digital technology, even if some may not have much to do with digital technology day-to-day. Decision-making in finance, employment, consumer transactions, politics, health and human services – all have undergone revolutionary change because of digital technologies, particularly since the advent of contemporary algorithmic technologies (variously described as artificial intelligence, machine learning, deep-learning, and so on). These changes, and the increasing digital connectivity of contemporary life, impact all Victorians in countless ways—some good, some bad, and others neutral.

## The role of technology supporting Victorians in distress or experiencing mental health crises

- In general, the application of digital technology in direct provision of mental health services, at least in terms of large-scale uptake, is at a reasonably early stage. In 2018, according to the Productivity Commission, around 20,000 people accessed supported online mental health services nationwide, with about 4,000 of these receiving clinician-supported online treatment.<sup>3</sup> However, digital modalities of care appear to be expanding greatly. This expansion has accelerated under the COVID-19 pandemic conditions (which I discuss at paragraph 26). Further, some types of interventions have been operational for quite some time. For example, internet interventions have been around now for about 20 years,<sup>4</sup> and telehealth, as an early example of the use of information and communication technology in mental healthcare, has been operational in Victoria in some form since the 1960s.
- 16 It is likely to be several years before we can judge the positive and negative effects of digital technology in the provision of mental health services in Victoria overall, but even then, the effects are likely to be complex and multi-faceted, making generalisation difficult.
- Technological innovations have the potential to bring positive change and help extend the best parts of the current approaches; for example, improving people's choices among good options for receiving support and connecting to others. Other changes will be relatively neutral and not impact the substance of care and support; an example might be mental health professionals scheduling appointments with consumers via mobile messaging apps. Still other changes have the potential to be negative for

85088324 page 3

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<sup>&</sup>lt;sup>3</sup> Productivity Commission, *Mental Health, Draft Report*, Canberra (2019) p.19.

<sup>&</sup>lt;sup>4</sup> Gerhard Andersson, 'Internet Interventions: Past, Present and Future', *Internet Interventions*, 12 (2018), 181-188.

people's mental health and extend the worst parts of current approaches or introduce new harms, such as creating modes of care that are expensive and ineffective, or which compromise people's dignity and privacy. There is a lot of hype around digital technology, which can make it hard to unpack the good, the bad and the trivial.

- It is helpful to first consider the various types of digital technologies being used in the mental health context, and the range of actors who use them. I conducted research on this topic with research assistance from Mr Timothy Kariotis.<sup>5</sup> Our findings suggest there are many different uses for digital technology in the direct provision of mental health care, including for the purposes of:
  - (a) Communication examples include telehealth and 'm-health' (mobile health) which provide an online interface through which clinical communication can occur, including between clinicians, or between service users and clinicians. Phone-based health or telehealth is perhaps prominent when people think of 'digital mental healthcare'. It is the most established mode of mental healthcare that uses information and communication technology and has the largest evidence-base.<sup>6</sup> According to On the Line Australia, the Victorian organisation 'Personal Emergency Services Australia' offered a confidential and anonymous telephone counselling service as far back as the 1960s.<sup>7</sup>
  - (b) Information Sharing in the health context, this category typically refers to the sharing of electronic health records. The Federal Government initiated My Health Record Scheme is a prominent example.
  - (c) Clinical Decision Support this category of technology ranges from presenting data in a certain way to aid clinicians in their decision making, to providing alerts and prompts for clinicians, to making treatment decisions without clinician input. An example is software designed to assist mental health practitioners with prognosis and treatment, such as computer assisted prescribing (to which I will return at paragraph 30(f)).
  - (d) Digital Therapies refers to the use of digital technologies as a treatment, such as mobile apps prescribed by doctors. The ReSET-O App, for example, was perhaps the earliest prescriptible mobile medical application in the mental health context in the world. It was approved for use by the US Food and Drug Administration (FDA) in 2018, and is described by the FDA as a 'prescription

85088324 page 4

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<sup>&</sup>lt;sup>5</sup> For a detailed discussion, see Piers Gooding, 'Mapping the Rise of Digital Mental Health Technologies: Emerging Issues for Law and Society', *International Journal of Law and Psychiatry*, 67 (2019), 101498.

<sup>&</sup>lt;sup>6</sup> See for example,. Andersson (n 4); G Andrews et al, 'Computer Therapy for the Anxiety and Depression Disorders Is Effective, Acceptable and Practical Health Care: An Updated Meta-Analysis', *Journal of Anxiety Disorders*, 55 (2018), 70-78.

<sup>&</sup>lt;sup>7</sup> See < https://ontheline.org.au/about-on-the-line/> [accessed 8 June 2020].

cognitive behavioural therapy intended to be used in addition to outpatient treatment under the care of a health care professional' for the treatment of substance use disorders. Another example of digital therapies is 'machine counselling', where natural language computer processing is used to imitate therapeutic conversation. For example, in 2019, the large-scale suicide helpline, On the Line Australia, announced the trial of a so-called 'virtual or robotic counsellor' as the first point of call for website users. Titled 'Claire', the computer program uses 'scripts and conversation prompts on the Suicide Call Back Service, asking multiple questions and answers, to figure what risk level the caller is, and where to direct them on the website'. Interestingly, as an organisation, On the Line Australia evolved out of Personal Emergency Services Australia, noted previously, which started tele-mental health consultations in Victoria in the 1960s.

- (e) Bio-informatics and Personalised Medicine or 'precision psychiatric medicine' is the relevant clinical practice in this broader category, and entails collection and 'Big Data' analysis of data concerning a person's genes, environment and lifestyle for the purposes of psychiatric treatment. This appears to be a relatively new sub-speciality within psychiatry, which is the subject of research in Victoria.<sup>12</sup>
- (f) Patient and/or Population Monitoring this category involves the tracking of individual health information or population health information over time. Data analytics, for example, could be used in efforts to identify people or communities at risk of suicide or psychosis.<sup>13</sup> Examples include artificial intelligence (AI) based suicide alerts on social media, but could also include Global Positioning System (GPS) monitoring of forensic psychiatric patients. GPS monitoring of forensic patients using electronic ankle bracelets does not occur in Victoria to my knowledge, but it does occur in South Australia and

<sup>&</sup>lt;sup>8</sup> See <a href="https://www.fda.gov/news-events/press-announcements/fda-clears-mobile-medical-app-help-those-opioid-use-disorder-stay-recovery-programs">help-those-opioid-use-disorder-stay-recovery-programs</a> [accessed 8 June 2020]. This app is not available in Australia, to my knowledge.

<sup>9</sup> See < https://www.suicidecallbackservice.org.au/> [accessed 11 June 2020].

<sup>&</sup>lt;sup>10</sup> Maggie Coggan, 'Virtual counsellor steps in to help out on suicide hotline' *Pro Bono Australia* (4 April 2019) < https://probonoaustralia.com.au/news/2019/04/virtual-counsellor-steps-in-to-help-out-on-suicide-hotline/> [accessed 8 June 2020].

<sup>11</sup> See <https://ontheline.org.au/about-on-the-line/> [accessed 23 June 2020].

<sup>&</sup>lt;sup>12</sup> Brisa Fernandes, et al, 'The New Field of "Precision Psychiatry" (2017) 15(1) *BMC medicine* 

<sup>&</sup>lt;sup>13</sup> See for example, Paolo Corsico, 'The Risks of Risk. Regulating the Use of Machine Learning for Psychosis Prediction', *International Journal of Law and Psychiatry,* 66 (2019), 101479; Mason Marks, *Artificial Intelligence Based Suicide Prediction*, SSRN Scholarly Paper, 29 January 2019 <a href="https://papers.ssrn.com/abstract=3324874">https://papers.ssrn.com/abstract=3324874</a>> [accessed 23 June 2020].

Queensland.<sup>14</sup> Technology that is used to measure individual health information could also include a mobile phone app that undertakes 'digital phenotyping, behavioral sensing, or personal sensing', in which a continuous stream of the data is gathered by a smartphone or device about an individual's behaviours, psychological states, and environments, forming a picture of their lived experience.<sup>15</sup> The data would then be fed back to a clinician or treating team to assist with treatment. Regarding population-level monitoring, Eastern Health's Turning Point in Melbourne received a grant from Google to use artificial intelligence (AI) to streamline the coding of national suicide-related ambulance data.<sup>16</sup> The aim is to help paramedics respond more effectively and ultimately decrease suicide rates.<sup>17</sup>

- (g) Service User Health Informatics this category of technology supports the actions of the service user within the health system, including personal health records or consumer decision aids. For example, the NHS in the UK is trialling an electronic mental health records and communication system called Healthlocker, which reportedly allows consumers to: "send confidential, secure messages to [their] care team; access [their] care plan; create and manage personal goals; access and create coping strategies; track [their] sleep," and so on. Another example is the CommonGround computer interface, used in the US, and developed by consumer advocates. It allows a service user, with the assistance of a peer worker, to add information they would like mental health professionals to know, including contextual personal information
- This range of functions suggests that the use of digital technology in mental health care is more complex than just the development of mental health apps, web platforms, or online-counselling services.
- Within any of the categories listed above, uses vary. Mental health professionals might use digital tools for referral coordination, clinical decision support and electronic health

<a href="https://www.ranzcp.org/news-policy/policy-and-advocacy/position-statements/electronic-monitoring-of-people-utilising-forensic">https://www.ranzcp.org/news-policy/policy-and-advocacy/position-statements/electronic-monitoring-of-people-utilising-forensic</a> [accessed 19 June 2020].

85088324 page 6

<sup>&</sup>lt;sup>14</sup> Royal Australian and New Zealand College of Psychiatrists, Position Statement 95: Electronic monitoring of people utilising forensic mental health services, May 2018

<sup>&</sup>lt;sup>15</sup> David Mohr, Katie Shilton and Matthew Hotopf, 'Digital Phenotyping, Behavioral Sensing, or Personal Sensing: Names and Transparency in the Digital Age', *npj Digital Medicine* 3 (2020),

<sup>1.</sup>Nick Forrester, 'Al Tech to Bolster Suicide Prevention Efforts in Australia', *ITbrief*<a href="https://itbrief.com.au/story/ai-tech-to-bolster-suicide-prevention-efforts-in-australia">https://itbrief.com.au/story/ai-tech-to-bolster-suicide-prevention-efforts-in-australia</a> [accessed 23 June 2020].

17 Ibid.

<sup>&</sup>lt;sup>18</sup> Chris Hollis et al, 'Identifying Research Priorities for Digital Technology in Mental Health Care: Results of the James Lind Alliance Priority Setting Partnership', *The Lancet Psychiatry*, 5 (2018), 845-854 <a href="http://www.sciencedirect.com/science/article/pii/S2215036618302967">http://www.sciencedirect.com/science/article/pii/S2215036618302967</a> [accessed on 23 June 2020].

records; they might use software for client identification and registration, healthcare provider decision-support, telemedicine, activity planning and scheduling, and healthcare provider training.

- Consumers might use digital platforms for peer group communication, consumer-led personal records, treatment decision-making tools, and a variety of self-directed apps and web-programs. One technology might have multiple uses. For example, an online platform or portal could simultaneously help a person communicate with mental health professionals, and also navigate among options in the overall mental health system. The National Disability Insurance Scheme ('NDIS') 'Myplace participant portal', for example, allows NDIS participants (or their plan and correspondence nominees) to view their NDIS Plan, update their personal contact details, manage services, and correspond with the National Disability Agency.
- Some of the technologies noted above, in terms of popular uptake, are experimental or in early stage-use, like the use of computer-generated 'machine counselling' and therapeutic 'chatbots'. Other categories, like telemedicine, are far older and better established.
- There is also a diversity of actors involved in the application of digital technology in mental healthcare. In addition to the main two user-groups consumers and mental health professionals other important actors include:
  - (a) Mental Health and Social Security System Co-ordinators: where digital technology is used in the administration and oversight of health and welfare systems, ranging from managerial actions on supply chain management, human resources, and service auditing, to oversight bodies that monitor the use of secondary personal data. An example in this category might be vital data gathering; for example, using basic computer processing to monitor rates of psychiatric medication prescription using routinely collected data. <sup>19</sup> I return to the role of digital technologies in monitoring service provision in paragraph 30(f).
  - (b) Data Management Services: These services assist with the use and management of data. They also supply the technology underlying other initiatives, such as the data storage technology behind an electronic health record, GPS monitoring systems, online therapeutic platforms, or mental health apps.

85088324 page 7

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<sup>&</sup>lt;sup>19</sup> See for example, Lisa G Pont et al, 'Leveraging New Information Technology to Monitor Medicine Use in 71 Residential Aged Care Facilities: Variation in Polypharmacy and Antipsychotic Use', *International Journal for Quality in Health Care*, 30.10 (2018), 810.

- (c) Education Providers: Ideas from the field of mental healthcare have expanded into education and there is evidence of the digitisation of student mental health information. I refer at paragraph 39 to a case in which a Melbourne high school that inadvertently published records concerning students' mental health.
- (d) **Social Media Companies:** Social media companies are increasingly seeking ways to address potential mental health crises or suicidal actions of users, and may be engaging in initiatives that could be considered mental health interventions. A prominent example is Al-based suicide alerts by social media companies that instigate the despatch of first-responders, <sup>20</sup> though it is not clear if this practice has been used in Victoria.
- If the use of digital technology in mental health care continues expanding, other likely domains of use include the **criminal justice system** (for example, algorithmic risk assessment of offenders, as in the US, or GPS monitoring of forensic psychiatric patients, as in Queensland and South Australia), **workplaces** (for example, online or digital platforms for employee mental health and wellbeing); and in **consumer transactions** (in which private companies, like insurance companies or data brokers, collect data about consumers that could be considered mental health data).
- Having outlined the various functions of digital technology, and several domains of use, I would like to emphasise a related point: it is not entirely clear the extent to which these technologies are being used in mental healthcare Victoria. There is an information gap as to the many and varied ways these digital technologies are being employed to promote the mental health of Victorians. The implication of this information gap is that it is harder to make clear, transparent decisions about the role of technologies in the Victorian mental health system, and harder to assess the outcomes and benefits for consumers and the broader community.
- The present pandemic conditions due to COVID-19 have accelerated the digitisation and virtualisation of mental healthcare. The Federal Minister for Health, the Hon Greg Hunt MP, recently reported that after the addition of telehealth under the Medicare Benefits Schedule in March, over 10 million services were delivered to over five million patients by early May,<sup>21</sup> of which a significant portion were mental health-related. The Minister described the significance of including mental healthcare in telehealth services, stating that 'changes that would otherwise have taken 10 years [were] done in 10

<sup>&</sup>lt;sup>20</sup> Mason Marks, *Artificial Intelligence Based Suicide Prediction*, SSRN Scholarly Paper, 29 January 2019 <a href="https://papers.ssrn.com/abstract=3324874">https://papers.ssrn.com/abstract=3324874</a>> [accessed 24 June 2020].

<sup>21</sup> See <a href="https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/international-world-">https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/international-world-</a>

<sup>&</sup>lt;sup>21</sup> See < <a href="https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/international-world-family-doctor-day">https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/international-world-family-doctor-day</a> [accessed 24 June 2020].

days'.<sup>22</sup> Similarly, in late May, Dr Ruth Vine, Deputy Chief Medical Officer of Australia for Mental Health, estimated, that approximately 50% of the clinical mental health sector had transitioned to using telehealth.<sup>23</sup>

- Minister Hunt and Dr Vine's points suggest that mental health services and organisations are likely to have developed governance structures for this major shift in a matter of weeks or months, whereas governance planning under typical conditions would have taken several years. Governance standards in digital healthcare are uncertain. Even for the longstanding practice of tele-mental healthcare, according to Sebastian Rosenberg, 'there are currently no agreed guidelines or standards against which these telehealth services should operate'. I understand that the Australian Commission on Safety and Quality in Health Care is developing National Safety and Quality Digital Mental Health Standards, the will bring some standardisation to the field, but more work will be required.
- Now is a good time to get a sense of what technologies are being used and what is on the horizon, as well as uncovering what types of governance legal, regulatory, or otherwise are needed that are specific to Victoria. The following may be required:
  - (a) human rights impact statements for significant new technologies in mental healthcare in light of the obligations imposed on public mental health services by the Victorian Human Rights Charter (Charter of Human Rights and Responsibilities Act 2006 (Vic));
  - (b) data protection impact statements for any providers wishing to introduce new measures that pose risks involving individuals' sensitive personal information;<sup>26</sup> and
  - (c) data governance guidelines, the development of which the Office of the Victorian Information Commissioner may take a prominent role.

<sup>&</sup>lt;sup>22</sup> See <https://www.pm.gov.au/media/press-conference-australian-parliament-house-act-12> [accessed 24 June 2020].

<sup>&</sup>lt;sup>23</sup> See <<u>https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/press-conference-about-20-million-for-health-and-medical-research-world-health-assembly-motion-and-covid-19>[accessed 23 June 2020].</u>

<sup>&</sup>lt;sup>24</sup> Sebastien Rosenberg, 'Mental health pandemic response: 10 years work next week' (blog) *Croakey* (22 May 2020) < <a href="https://croakey.org/mental-health-pandemic-response-10-years-work-next-week/">https://croakey.org/mental-health-pandemic-response-10-years-work-next-week/</a>> [accessed 23 June 2020].

<sup>&</sup>lt;sup>25</sup> See <<u>https://www.safetyandquality.gov.au/standards/national-safety-and-quality-digital-mental-health-standards></u> [accessed 8 June 2020].

<sup>&</sup>lt;sup>26</sup> In the EU, for example, A Data Protection Impact Assessment is required under the General Data Protection Regulations (GDPR) of the EU any time a project begins that is likely to involve "a high risk" to other people's personal information. The GDPR is often cited as a gold standard of data protection law. See <a href="https://gdpr.eu/data-protection-impact-assessment-template/">https://gdpr.eu/data-protection-impact-assessment-template/</a> [accessed 24 June 2020].

The Royal Commission is an excellent opportunity to make recommendations towards the responsible public governance of digital technologies in the mental health context. I would imagine that the proposed Collaborative Centre for Mental Health and Wellbeing would be in a good position to provide input on the way data-based technologies are being used in Victoria's mental health services.

## Opportunities presented by digital technology for the way people find, access and receive mental health services

- There are several benefits of digital technologies in mental health advanced in the literature. These include the following:
  - (a) Tele-health and web-based support can **break down geographical barriers** and provide effective care and support to people in distress.<sup>27</sup>
  - (b) In some cases, online mental health initiatives can facilitate confidential and anonymous help-seeking. This might be extremely important for certain groups, particularly those from small or marginalised communities; for example, people in remote or rural communities, LGBTIQ+ young people, and Indigenous people who are wary of sharing personal information.<sup>28</sup>
  - (c) There are free web-based programs, some of which may help people to manage their distress, or identify mental health issues, which can provide a quick, inexpensive and accessible resource for those with access to the internet.<sup>29</sup>
  - (d) Various kinds of digital technology can help **improve the availability of quality information** to help develop awareness of relevant services. This includes services and organisations outside the formal mental health system that may be helpful, such as sexual assault services, financial counseling, bushfire relief, and informal peer-run support groups for people experiencing distress or addiction. In Victoria, there are also examples of community-driven resources, such as the Burndawan online family violence resource, which was created by members of the Wadawurrung community of the Kulin nations.<sup>30</sup> The idea

30 See < https://burndawan.com.au/> [accessed 24 June 2020].

<sup>&</sup>lt;sup>27</sup> Dinesh Bhugra et al, 'The WPA-Lancet Psychiatry Commission on the Future of Psychiatry', *The Lancet Psychiatry*, **4**.10 (2017), 775, p.803.

<sup>&</sup>lt;sup>28</sup> See for example, Mission Australia, 'Accessibility and quality of mental health services in rural and remote Australia Submission' 80,

p.17.<a href="https://www.aph.gov.au/DocumentStore.ashx?id=097bdfbe-91ff-44f8-b4ab-ce14217ba1f5&subId=612899">https://www.aph.gov.au/DocumentStore.ashx?id=097bdfbe-91ff-44f8-b4ab-ce14217ba1f5&subId=612899</a> [accessed 9 June 2020]; Paul Byron, et al. "You learn from each other": LGBTIQ Young People's Mental Health Help-seeking and the RAD Australia Online Directory' (2016) Western Sydney University Young and Well Cooperative Research Centre, Sydney, p.51; see also <a href="https://burndawan.com.au/">https://burndawan.com.au/</a> [accessed 9 June 2020].

<sup>&</sup>lt;sup>29</sup> See generally, Productivity Commission, *Mental Health, Draft Report*, Canberra (2019), Ch 6.

behind the creation of this resource was to improve the information and advice available on family violence for their own community, in ways that respected their concerns around privacy and cultural respect.

- (e) Digital technology could be used to **improve the range of meaningful choices available** to consumers and supporters. For example, 'personalised' and 'user-controlled' health records are emerging, such as the *Healthlocker* service in the UK, as are computer-interfaces in health services, which allow service users to contextualise diagnoses, plan for crises, and record preferences (both of which I described above at paragraph [18(g)]).
- (f) There is also a positive role for data-driven digital technologies in the monitoring of services, and collection of vital statistics by monitoring bodies, health system co-ordinators, managers and advocates. A lot of emphasis has been placed on digital technology in therapeutic encounters but one area I believe is overlooked, is the use of digital technology in vital data collection.

As noted, Turning Point is aiming to use AI to streamline the coding of national suicide-related ambulance data to help paramedics respond more effectively and ultimately prevent potential suicides. The project will reportedly annotate a large database of clinical records, and use a machine-learning model to augment and accelerate the time-consuming work of categorising and filtering through tens of thousands of records per month.<sup>31</sup>

Another example comes from NSW, where Lisa Pont and colleagues used new information technology to monitor medicine use in 71 residential aged care facilities in Australia, with one aim being to identify the excessive prescription of anti-psychotic medication.<sup>32</sup> Their digital initiative used routinely collected data to detect high rates of psychotropic medication-use in aged care facilities that could not be easily explained, flagging the need for further checks.

Similarly, Johanna Westbrook and colleagues produced some evidence to show that commercial electronic prescribing or 'e-prescribing' systems could reduce hospital in-patient prescribing error rates, including in a psychiatric ward in a large-scale Sydney hospital.<sup>33</sup> These systems did so mainly by reducing the number of incomplete, illegal, or unclear medication orders.

<sup>&</sup>lt;sup>31</sup> Forrester (n 16).

Lisa Pont, et al, 'Leveraging New Information Technology to Monitor Medicine Use in 71 Residential Aged Care Facilities: Variation in Polypharmacy and Antipsychotic Use', International Journal for Quality in Health Care, 30.10 (2018), 810.

<sup>&</sup>lt;sup>33</sup> Johanna I Westbrook et al, 'Effects of Two Commercial Electronic Prescribing Systems on Prescribing Error Rates in Hospital In-Patients: A Before and After Study', *PLOS Medicine* e, 9.1 (2012), 1001164.

From a regulatory perspective, these findings make a case for giving priority to improving the quality and accessibility of the data in electronic systems over investing in stand-alone, resource-intensive auditing processes.

From a rights-based perspective, such measures offer preventative steps to uphold the right to the enjoyment of the highest attainable standard of health, the right to physical and mental integrity, and the right to be free from cruel, inhuman or degrading treatment.

These are just some of the benefits advanced in the scholarly literature. Australia has some of the most prominent clinical researchers worldwide on e-mental health initiatives, and they make a strong case for the benefits of online mental health services. The Black Dog Institute, for example, states that 'formal integration of eMental Health programs to our health care system will significantly reduce the social and financial burden of mental illness' and can 'address serious access gaps to mental illness education, prevention and treatment services'. This view is reflected in the clinical literature more broadly. The services is the scholar program of the services of the services is reflected in the clinical literature more broadly.

## The limitations and challenges of digital technology in providing alternatives to face to face and traditional service delivery options

- In terms of **limitations and challenges**, the following concerns have been raised by various researchers and advocates:
  - (a) When it comes to digital therapies, there seems to be general agreement that measures will only remain positive if they augment rather than replace quality face-to-face support. Chris Hollis and colleagues conducted a large-scale participatory study in the UK, in which 664 'people with lived experience of mental health problems and use of mental health services, their carers, and health-care practitioners' were asked to prioritise research objectives on digital technology in mental healthcare.<sup>37</sup> The top research priority proposed by the group was to determine 'the benefits and risks of delivering mental health care through technology instead of face-to-face' and consider the impact of removing 'face-to-face human interaction'.<sup>38</sup> It is reasonable to expect similar results for

<sup>&</sup>lt;sup>34</sup> See, for example, the Black Dog Institute <<u>www.blackdoginstitute.org.au></u>; the Centre for Mental Health Research <<u>https://rsph.anu.edu.au/research/centres-departments/centre-mental-health-research></u>; Orygen's digital mental health division, eOrygen

<sup>&</sup>lt;a href="https://www.orygen.org.au/Our-Research/Research-Areas/Orygen-Digital">https://www.orygen.org.au/Our-Research/Research-Areas/Orygen-Digital</a> [accessed 24 June 2020].

<sup>&</sup>lt;sup>35</sup> See < <a href="https://www.blackdoginstitute.org.au/docs/default-source/research/saving-lives-nationally-integrated-ehealth.pdf?sfvrsn=0>" [accessed 24 June 2020],</a>

<sup>36</sup> See for example,. Bhugra et al (n 27).

<sup>&</sup>lt;sup>37</sup> Hollis et al (n 18).

<sup>&</sup>lt;sup>38</sup> Ibid p. 7.

Victoria and Australia more generally,39 though there is a research gap concerning the views on online mental health interventions of Australian consumers, families and carers, and professionals.

- (b) Data protection is a serious issue raised by digital mental health initiatives, raising matters of privacy, confidentiality and general data security. This topic warrants elaboration, which I will provide in the next section.
- (c) On a purely practical level, new technologies may mean increased pressure on service providers to increase multi-tasking and workloads in collecting, inputting, organising, and constantly updating digital records, which, paradoxically, may reduce time for teamwork and face-to-face engagement.<sup>40</sup>
- While there is strong evidence for the benefits of interventions like telehealth (d) and certain kinds of online support for mental healthcare, 41 there are serious limits to the evidence for other types of digital initiatives. Consider that there are now reportedly 10,000+ mobile apps that are designed for mental health support. 42 Simon Leigh and Steve Flatt characterise such apps as suffering from a 'frequent lack of an underlying evidence base, a lack of scientific credibility and subsequent limited clinical effectiveness'. 43 They are quick to point out that app quality is variable, and that some apps have a stronger evidence base. However, they warn that government health agencies should exercise caution in the apps they promote.44

There is also the matter of how people engage with the apps in the real-world, outside of control conditions. A systematic review by Amit Baumel and colleagues, found that only 4% of mental health users continue using mental

See for example, J Marc Overhage and David McCallie, 'Physician Time Spent Using the Electronic Health Record During Outpatient Encounters', Annals of Internal Medicine, 172.3 (2020), 169.

<sup>&</sup>lt;sup>39</sup> See for example,. National Mental Health Commission, 2014 Contributing Lives Review, 2014, p.12 <a href="https://www.mentalhealthcommission.gov.au/Monitoring-and-Reporting/national-">https://www.mentalhealthcommission.gov.au/Monitoring-and-Reporting/national-</a> reports/2014-Contributing-Lives-Review> [accessed 6 June 2018].

Internet-delivered cognitive behaviour therapy is well established, for example, with numerous reviews and meta-analyses to support the effectiveness of certain programs for a variety of mental health conditions in different population groups. Gerhard Andersson et al, 'Internetdelivered Psychological Treatments: From Innovation to Implementation', World Psychiatry, 18.1 (2019),20. Researchers at the Black Dog Institute argue that there is a robust evidence base for tele-counselling support, and there's an emerging evidence base for automated and semi-automated cognitive behavioural therapy software. See

<sup>&</sup>lt;a href="https://www.blackdoginstitute.org.au/research/key-research-areas/emental-health">https://www.blackdoginstitute.org.au/research/key-research-areas/emental-health</a> [accessed 23 June 2020].

42 Mark Erik Larsen et al, 'Using Science to Sell Apps: Evaluation of Mental Health App Store

Quality Claims', npg Digital Medicine, 2.1 (2019), 1.

<sup>&</sup>lt;sup>43</sup> Simon Leigh and Steve Flatt, 'App-Based Psychological Interventions: Friend or Foe?', Evidence-Based Mental, 18.4 (2015), 97, p.97.

44 Ibid.

health apps after two weeks.<sup>45</sup> 'Continued use' in this study is measured merely by *opening* the app.

There are real risks that come from overhyping technology without a commensurate evidence base. On an individual level, one result could be to shape individual consumers and mental health professionals' preferences and expectations about treatment. For example, a person may feel that a mental health app has 'proven' she or he has a particular disorder or may encourage them to see their distress as a medical issue. <sup>46</sup> On a macro-level, over-stating the evidence can alter how funding is directed, and again, draw institutional resources away from where they're needed most.

- Hype surrounding new technologies creates a risk of 'solutionism'. 47 (e) Solutionism refers to the (flawed) belief that every social problem has a technological fix, and that simple technological fixes are possible for what, in reality, are highly complex social issues. The mental health of Victorians is a perfect example of a deeply complex social and health issue. It may be claimed, for example, that a chat-bot for a suicide prevention initiative could engage with five or even 5,000 people at a time, in contrast to a human counsellor who can only speak with one person at a time. I don't mean to reject these or other aspirations to engage with technology creatively to help people in distress, but there are valid concerns that standardised digital packages of mental health care and the reduction of complex encounters of human care to computerreplicated encounters, will not be able to transform service provision in the way some commentators are suggesting. This is perhaps especially so where neither consumers nor families, nor even a broad base of mental health professionals, are really driving the call for digital service provision.
- (f) At present, there is little evidence that digital therapies and other digital technologies in mental health care are a priority for consumers and carers. I do not mean to speak for these groups, but caution is needed to ensure that resources aren't put into digital initiatives and drawn away from the priorities of consumers and family/carers. For example, nowhere do VMIAC or Tandem refer to internet-based or digital mental health initiatives in their submissions to the Royal Commission (nor in their public submissions to the

85088324 page 14

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<sup>&</sup>lt;sup>45</sup> Amit Baumel et al, 'Objective User Engagement With Mental Health Apps: Systematic Search and Panel-Based Usage Analysis', *Journal of Medical Internet Research* e, 21.9 (2019), 14567. <sup>46</sup> Lisa Parker et al, 'Mental Health Messages in Prominent Mental Health Apps', *The Annals of Family Medicine*, 16.4 (2018), 338. <sup>47</sup> Evgeny Mesozay, To Say To

<sup>&</sup>lt;sup>47</sup> Evgeny Morozov, To Save Everything, Click Here: Technology, Solutionism, and the Urge to Fix Problems That Don't Exist (Penguin UK, 2013) ('To Save Everything, Click Here').

Productivity Commission). 48 Instead, VMIAC call for services that are 'helpful, do no harm, and respect and uphold human rights', while Tandem call for services that are 'safe, inclusive, fair and funded'. Where digital initiatives contribute to these ends, I suspect they will be welcome, but more work is required to ensure this is the case, and research is needed to garner the views of the groups who are primarily impacted.

- Digital equity will remain a significant issue. Some people simply do not have (g) access to digital technologies. Research by Dan Robotham and colleagues, in a five year study on digital exclusion in the UK, which involved 241 participants, suggests the 'digital divide' is very difficult to overcome. 49 They suggest that improving access to digital technologies for people who lack the knowledge, skill and financial resources could form part of an essential service for mental health. Digital inclusion strategies may be required to prevent people becoming excluded from both digitised mental health services and from society in general.
- (h) The messaging of widely available digital mental health applications can be excessively medicalised. In what appears to be the largest-scale survey of the messaging of mental health apps, Lisa Parker and colleagues argued that prominent mental health apps tend to over-medicalise states of distress and may over-emphasise 'individual responsibility for mental well-being'. There may be legitimate reasons to seek to de-medicalise some approaches to distress in digital mental health initiatives. In his book on the future of psychiatry, Nikolas Rose argued that 'most forms of mental distress are inextricably linked to problems of poverty, precarity, violence, exclusion and other forms of adversity in people's personal and social experiences, and are best addressed not by medicalization, but by low intensity but committed and durable social interventions guided by outcomes that are not measured in terms of symptom reduction, but by the capacities that people themselves desire in their everyday lives'.50

Digital initiatives, therefore, could include harnessing the enormous goodwill in community to assist people, including people's informal or 'natural' supports, peer supports and so on, as distinct to health-focused interventions. (Again, this

<sup>&</sup>lt;sup>48</sup> See < https://www.vmiac.org.au/wp-content/uploads/Post-draft-report-submission-to-PC-from-VMIAC-FINAL.pdf>; <a href="https://s3.ap-southeast-2.amazonaws.com/hdp.au.prod.app.vic-">https://s3.ap-southeast-2.amazonaws.com/hdp.au.prod.app.vic-</a> rcvmhs.files/9215/6513/7243/Victorian Mental Illness Awareness Council.pdf>; <a href="https://s3.apsoutheast-2.amazonaws.com/hdp.au.prod.app.vic-rcvmhs.files/5815/6513/7243/Tandem.pdf; https://www.tandemcarers.org.au/images/Tandem%20Feedback%20 Productivity%20Commiss ion%20Inquiry%20into%20Mental%20Health%20Jan2020.pdf> [accessed 23 June 2020].

Dan Robotham et al, 'Do We Still Have a Digital Divide in Mental Health? A Five-Year Survey Follow-Up.', *Journal of Medical Internet Research e,* 18.11(2016), 309. <sup>50</sup> Nikolas Rose, *Our Psychiatric Future* (John Wiley & Sons, 2018), p.148.

is certainly not to detract from the importance of targeted, clinical and acute services).

The National Mental Health Commission, for example, recently promoted online initiatives like *eFriend*<sup>51</sup> and *Crisis Heroes*<sup>52</sup> during the COVID-19 lock-down period, both of which are online community platforms designed for support to be offered and received. I am not aware of any research on how much impact these platforms have had, but they illustrate the potential to harness community goodwill and mainstream efforts to promote social inclusion to reach people who are isolated or experiencing distress.

(i) Some scholars and service user advocates have raised the prospect that digital technologies in mental healthcare (and healthcare in general) will create new, and poorly understood, forms of surveillance of the encounter between doctors and patients/consumers,<sup>53</sup> which could undermine therapeutic relationships and violate the fundamental rights of service users.

#### Data Protection, Privacy and Confidentiality

- The literature suggests that the personal data gathered by digital mental health therapies like apps, but also websites are typically haphazardly protected and insufficiently regulated. The amount and nature of the collection is often unclear.<sup>54</sup>
- For example, in 2019 Privacy International analysed more than 136 popular web pages related to depression in the European Union. The websites were chosen to reflect those that people would realistically find when searching for help online. The authors found that about 98 percent of the pages contained a third-party element, which enabled targeted advertising from large companies like Google, Amazon, and Facebook. Knowledge of a user's distress would allow companies to advertise specific treatments, services or financial products. Most websites failed to comply with the EU General Data Protection Regulation, which is often presented as a leading standard for data protection law. Two of the sites examined in the report were Australian, and included self-assessment tools for depression, anxiety and bipolar, though it was not stated whether these particular sites contained a third party element.

<sup>&</sup>lt;sup>51</sup> See <<u>https://efriend.org.au/</u>> [accessed 23 June 2020].

<sup>&</sup>lt;sup>52</sup> See <a href="https://www.crisisheroes.com/">https://www.crisisheroes.com/</a>> [accessed 23 June 2020].

<sup>&</sup>lt;sup>53</sup> See for example,, Deborah Lupton, 'Critical Perspectives on Digital Health Technologies', *Sociology Compass*, <u>8.12</u> (2014), 1344; Leah Harris, 'The Rise of the Digital Asylum', *Mad In America* (15 September 2019) <a href="https://www.madinamerica.com/2019/09/therise-of-the-digital-asylum/">https://www.madinamerica.com/2019/09/therise-of-the-digital-asylum/</a>; Adrian Guta, Jijian Voronka and Marilou Gagnon, 'Resisting the Digital Medicine Panopticon: Toward a Bioethics of the Oppressed', *The American Journal of Bioethics*, 18.9 (2018) 18(9), 62.

<sup>&</sup>lt;sup>54</sup> See generally, Gooding (n 5).

<sup>&</sup>lt;sup>55</sup> See <<u>https://privacyinternational.org/campaigns/your-mental-health-sale</u>> [accessed 23 June 2020].

- 35 Privacy laws that underpin most of the relevant regulatory schemes, like the federal Privacy Act 1988 (Cth), were generally written prior to the expansion of the digital health market and the era of 'big data', and may not provide robust protection for consumers' sensitive personal information.<sup>56</sup> Health and data privacy laws in Australia appear to omit requirements in relation to digital mental health initiatives. Where requirements do exist, they often lack detailed regulations or remain 'siloed, with no single sector holding comprehensive oversight'.57
- 36 Without robust protections, there is a risk that poor consumer-trust will have negative flow-on effects for mental health service use, which may serve as yet another barrier to people accessing preventive support. The Victorian Consumer Policy Resource Centre captured this concern in its report titled, A Day in the Life of Data:

'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. 58

- 37 When help-seeking is leveraged against a person's interest, people will be less likely to seek help.
- 38 Apps have also raised concerns about data misuse. In 2015, the National Health Service of England closed its App Library after a study found that 28% of the apps lacked a privacy policy<sup>59</sup> and one app even transmitted personally identifiable data that its policy claimed would be anonymous. 60 As noted, there are currently 10,000+ mental health-focused apps available worldwide 61 and they constitute the largest group of

<sup>57</sup> Lisa Parker et al, 'How Private Is Your Mental Health App Data? An Empirical Study of Mental Health App Privacy Policies and Practices', International Journal of Law and Psychiatry, 64 (2019), 198.

<sup>&</sup>lt;sup>56</sup> Larsen et al (n 42).

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) <a href="https://cprc.org.au/wp-content/uploads/CPRC-Research-Report A-Day-in-the-Life-of-page-12">https://cprc.org.au/wp-content/uploads/CPRC-Research-Report A-Day-in-the-Life-of-page-12">https://cprc.org.au/wp-content/uploads/CPRC-Research-Repo Data final-full-report.pdf> [accessed 23 June 2020].

Kit Huckvale et al. 'Unaddressed privacy risks in accredited health and wellness apps: a

cross-sectional systematic assessment.', *BMC medicine*, 13.1 (2015), 214. <sup>60</sup>Paul Wicks and Emil Chiauzzi, 'Trust but verify'–five approaches to ensure safe medical apps'.BMC medicine, 13.1 (2015), 205.

Michelle Ng et al. 'User engagement in mental health apps: a review of measurement, reporting, and validity.' Psychiatric Services, 70.7 (2019), 538-544.

'condition-specific' apps in the overall health app market. Some mental health apps, commendably, use transparent platforms and open source code<sup>62</sup> but two recent studies found that nearly half of the popular mental health apps surveyed did not have a privacy policy that informed users about how and when personal information would be collected or shared with third parties.<sup>63</sup>

- 39 Data theft will become increasingly prevalent. For example, in the US in 2017, a mental health service provider in Texas notified 28,434 service users whose data was allegedly stolen by a former employee.<sup>64</sup> Human error also has a well-documented history of causing data breaches. In Victoria in 2017, the Australian Associated Press reported that a high school in Strathmore publicly posted sensitive personal data about students online, including their mental health history. 65 This incident is a flashing amber light for anyone interested in the role of digital technology in providing mental health care, and particularly in storing people's mental health history digitally. This issue may be acute for young people given both the inherent sensitivity of young people's personal information and the greater propensity for youth-focused services to have a digital component. It is one thing to digitise information that a child was diagnosed with bronchitis but quite another to make a permanent digital record that she or he was diagnosed with childhood personality disorder. No one should be followed around by a mental health diagnosis their whole life. Digital records provide a serious risk of sensitive personal information being held in perpetuity, and potentially being accessible by multiple government agencies and non-government actors.
- These concerns are not merely the concerns of privacy advocates. For example, a 40-author report for the World Psychiatric Association's Commission on the Future of Psychiatry stated that '[a]t present, serious concerns remain regarding the privacy, transparency, and confidentiality of digital health tools.'66 The authors, all of whom are prominent psychiatrists, warn of 'commercialised, unproven treatments entering the

<sup>62</sup> John Torous et al. 'Creating a digital health smartphone app and digital phenotyping platform for mental health and diverse healthcare needs: an interdisciplinary and collaborative approach.', *Journal of Technology in Behavioral Science*, 4.2 (2019), 73-85.

66 Bhugra et al (n 27).

Lisa Parker et al., 'How private is your mental health app data? An empirical study of mental health app privacy policies and practices.', *International journal of law and psychiatry,* 64 (2019),198-204; Kristen O'Loughlin et al., 'Reviewing the data security and privacy policies of mobile apps for depression.', *Internet interventions,* 15 (2019), 110-115.

64 HIPAA. (2017, December 5). PHI of 28,000 Mental Health Patients Allegedly Stolen by

<sup>&</sup>lt;sup>64</sup> HIPAA. (2017, December 5). PHI of 28,000 Mental Health Patients Allegedly Stolen by Healthcare Employee. *HIPAA Journal*. Retrieved from <a href="https://www.hipaajournal.com/phi-28000-mental-health-patients-stolen-by-healthcare-employee/">https://www.hipaajournal.com/phi-28000-mental-health-patients-stolen-by-healthcare-employee/</a>> [accessed 23 June 2020].

Australian Associated Press 'Melbourne student health records posted online in 'appalling' privacy breach' [22 August 2018].

medical marketplace with detrimental effect' including 'many low-quality and even dangerous apps'. 67

Some mental health service user groups, including VMIAC, have raised concerns about data security and privacy concerning the My Health Record, citing fears of discrimination if digitised personal mental health histories were stolen, leaked or sold. 68

#### Known Risks and Unforeseen Consequences

- Any proposed benefits of digital initiatives in mental health care must be weighed against the unavoidable reality that digital technologies increase the susceptibility of individuals and communities to certain types of harms to health and safety, including decreased privacy, third party organisations leveraging information against users' interests, reputational injury, and discrimination. Proponents of digital mental health technologies need to go beyond vague notions of 'privacy' or 'innovation' to address broader social consequences of the collection, aggregation, and use of personal health information.
- Although there are significant gaps in the research on how consumers (and carers) experience the digitisation or virtualisation of services, research on broader health services suggest that views are likely to be complex. Some consumers may feel as if they have little control over their doctors' decision to use these technologies and may wish to return to a more traditional patient-doctor/consumer-provider relationship; others may find that the provision of such technologies allows them greater control and choice over their healthcare. Digital health technologies can extend medical observation; using them responsibly would include giving consumers/patients the opportunity to avoid this observation.
- The full range of consequences of these technologies are potentially poorly understood even by experts, particularly given the vast reams of data that can be transported, the exponential growth in the size and complexity of the digital sphere, and the new and emerging uses to which personal data are being put. Given these uncertainties, a precautionary approach may be required.

<sup>67</sup> Ibid.

<sup>&</sup>lt;sup>68</sup> Gaebler, S., Maggie Toko, M., Jenkinson, S., & Wortham, R., (2018). *Joint letter to Minister Hunt – My Health Record*. Retrieved from <a href="http://being.org.au/2018/08/joint-letter-to-minister-hunt-my-health-records/">http://being.org.au/2018/08/joint-letter-to-minister-hunt-my-health-records/<>> [accessed 23 June 2020].

<sup>&</sup>lt;sup>69</sup> See generally, Lupton (n 53).

<sup>&</sup>lt;sup>70</sup> lbid.

## The strengths and limitations of current digital resources used to provide information about available mental health services

- When digital resources that provide information about services work well, they provide an easy-to-use platform to help people get connected safely to the support they need. I suspect that equitable practice dictates these resources are available in a range of languages that are relevant to a particular population, are culturally sensitive where required, and conform with web accessibility guidelines for people with additional accessibility needs (for example, screen-reader accessible websites, and Easy English options).
- Good resources would facilitate direct service provision, treatment and access to resources, as well as opportunities for social inclusion and mutual aid (that is, voluntary reciprocal exchange of information and support). Resources could help both those with moderate and more severe conditions to connect to relevant services, and to problem solve and explore the kinds of services that are relevant to them, whether geographically, culturally, or according to a person's values.
- I am more familiar with the resources available in two areas: first, legal issues facing people subject to *the Mental Health Act 2014* (Vic) (the Act); and second, peer-run online resources.
  - (a) Regarding the use of the Act, websites like the Victorian Government, Victoria Legal Aid, the Office of the Public Advocate, and the Independent Mental Health Advocacy service appear to have simple and clear information about the rights of people subject to involuntary treatment under the Act.
  - (b) In terms of peer-support services, some consumer-run online resources appear highly informative, including OurConsumerPlace, VMIAC, and PeerZone.<sup>71</sup>
- Finally, good quality information would include services and organisations outside the formal mental health system that may be helpful, such as sexual assault services, family violence services, financial counseling, bushfire relief services, services for culturally and linguistically diverse people, services for Aboriginal and Torres Strait Islander people and informal peer-run support groups for people experiencing distress or addiction.

Using digital resources to support people from diverse communities to access information on the range of mental health services available

85088324 page 20

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<sup>&</sup>lt;sup>71</sup> See for example, <<u>www.ourconsumerplace.com.au></u> [accessed 24 June 2020] and <<u>www.peerzone.info></u>.[accessed 24 June 2020].

- Consumers are in a unique position to identify the localised, social and personal dimensions of distress. Consumers are driving creative, practical programs to the complex social problems surrounding mental health crises. They generally call for measures to help people articulate distress in ways that make sense to the person, in ways that relate to the adversity they are facing, be it stress, poverty, exclusion, racism, violence, and so on this pluralistic and deliberative approach is likely to be as appropriate for the design and delivery of online resources as for physical services.
- Different cultural and social groups (such as Aboriginal and Torres Strait Islanders, LGBTIQ+, veterans and international students) are also well positioned to help people from particular communities to articulate distress in meaningful ways, and connect individuals in crisis to the support they need, be it mental health or otherwise.
- An example of a locally-driven initiative is the Burndawan online family violence resource, which I describe above at paragraph [30(d)]. Burndawan is based on a Wadawurrung word meaning "safe". The resource was designed in a highly participatory way, and in a way that was sensitive to the privacy and data security concerns of Aboriginal and Torres Strait Islander communities. Burndawan is a good example of the type of participatory, community-driven design process that can improve the digital resources available to diverse communities.

## Strengthening the role of people with lived experience in the co-production of the future digital agenda for mental health

- From a pragmatic perspective, the involvement of consumers 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. Participatory methods also align with human rights standards to actively involve persons with disabilities in decisions about the law, policy and programming that concerns them.
- 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 manner, created to address one issue without sufficient thought to harmful flow-on consequences. Poor user consultation also

85088324 page 21

<sup>&</sup>lt;sup>72</sup> I should acknowledge that I am a Research Fellow at the research institute that partially funded this project, the Melbourne Social Equity Institute at the University of Melbourne.
<sup>73</sup> Bhugra et al (n 27) p.801.

<sup>&</sup>lt;sup>74</sup> See United Nations Convention on the Rights of Persons with Disabilities, 2006, Preamble p.15.

<sup>&</sup>lt;sup>75</sup> Rishi Duggal, Ingrid Brindle and Jessamy Bagenal, 'Digital Healthcare: Regulating the Revolution', *BMJ*, 360 (2018), 2.

increases the likelihood of wasted resources—as appears to be the case with the UK Care.data scheme to extract data from GP surgeries into a national database, for example, which was terminated.<sup>76</sup> Deliberative, participatory development is also important because the convergence of medicine and technology tends to emerge from a concentration of power in a myriad of ways: government health agencies, venture capital and Big Technology companies, universities with large-scale infrastructure for tech development, professional associations, and so on. To ensure greater equity in design, development and regulation, Adrian Guta, Jijian Voronka and Marilou Gagnon call for 'interdisciplinary empirical research on the implications of these technologies that centers the experiences and knowledge of those who will be most affected'. 77 Their recommendation to centre the experiences and knowledge of the primarily affected group is not shared across the literature. Many studies that point to widespread agreement among health-care providers, medical associations, industry, and governments about the promise of digital technology in psychiatric care, do not include service user organisations among the list of enthusiastic actors. Whether this is due to oversight on the part of the authors or ambivalence among service user organisations is not clear.

#### Social inclusion

- Before concluding, I will briefly discuss the issue of social inclusion. My knowledge of this topic knowledge draws from a research project I led, titled, 19 Stories of Social Inclusion. The findings were published online, 78 and included a systematic literature review investigating how the social inclusion of adults with disability is conceptualised in policy research in Australia. 79 This work was undertaken with Professor Keith McVilly and Ms Julie Anderson.
- We defined social inclusion with reference to the work of Francisco Azpitarte, as a way to understand poverty and disadvantage that goes beyond a person's income and assets, to include 'other essentials for their participation in society, such as access to education, health services and transport, and non-material aspects such as stigma and denial of rights'. The literature review suggests that Australian research on social inclusion of people with disability, including mental health conditions and psychosocial disabilities, has focused on providing access to resources, opportunities and capabilities that all citizens need to learn, work, and engage in society. Religion, cultural and

<sup>&</sup>lt;sup>76</sup> Fiona Godlee, 'What Can We Salvage from Care.Data?', BMJ, 354 (2016)...

<sup>77</sup> Guta, Voronka and Gagnon (n 53), p.64.

<sup>&</sup>lt;sup>78</sup> See < https://www.19stories.org/about > [accessed 24 June 2020].

<sup>&</sup>lt;sup>79</sup> Piers Gooding, Julie Anderson and Keith McVilly, 'Disability and Social Inclusion "Down Under": A Systematic Literature Review', *Journal of Social Inclusion*, 8.2 (2017), 5.

<sup>&</sup>lt;sup>80</sup> F Azpitarte, *Social exclusion monitor bulletin. Research Bulletin.* Melbourne, Australia: Brotherhood of St Laurence (2013).

linguistic diversity, gender, sexual identity, and more recently, disability, all provide an important lens through which to understand and address social exclusion.

One of our project advisors, Professor Helen Dickinson, remarked that policy discourses on social inclusion often focus on people with disability or mental health conditions and not the broader communities in which they live. She writes:

'To some extent this is because [the policies and services] seek to 'fix' people with disability and not the broader population, just as some initiatives to address gender inequities have been critiqued for their focus on 'fixing women'.'81

In a similar vein, Jane Rosengrave, a prominent Victorian disability advocate who shared her story for the 19 Stories Project, commented that 'it's ... strange because sometimes only people with disabilities are asked about social inclusion! Why don't people without disability get asked about it?'82 These comments suggest that efforts to address exclusion could benefit from developing the accessibility of communities as much, if not more than, focusing on the capabilities of individuals with mental health conditions and psychosocial disabilities.

# Adequacy of the current Victorian anti-discrimination framework and avenues for improvement

In respect of data security issues (which I discuss above at paragraphs [33-41]), *The Equal Opportunity Act 2010* (Vic) and *Disability Discrimination Act 1992* (Cth) may need to be amended to ensure that discrimination on mental health grounds by online businesses is covered. This could include discrimination by insurance companies, social media companies and other businesses that may collect or use sensitive personal information concerning the mental health of Victorians. This amendment would be consistent with the goals and legislative history of anti-discrimination laws and would remove ambiguity regarding the status of websites, social media platforms, and other online businesses.<sup>83</sup>

In addition to modifying antidiscrimination laws, there is a need for robust data protection laws that acknowledge that mental health and disability-related data can be mined from multiple sources, including from disability service and healthcare systems.

<a href="https://ssrn.com/abstract=3338209">https://ssrn.com/abstract=3338209</a> [accessed 24 June 2020].

<sup>&</sup>lt;sup>81</sup> Helen Dickinson, 'Disability and Social Inclusion: What are the Policy Messages of 19 Stories?' <a href="https://af92f37f-eedb-481d-9385-">https://af92f37f-eedb-481d-9385-</a>

<sup>4</sup>afd5a34cf57.filesusr.com/ugd/c77aca 1c6a84073ce143afbe67049990bf1a69.pdf> [accessed 15 June 2020].

82 Jane Rosengrave, 'You Only Live Once!' < https://www.19stories.org/copy-of-story-14-2>

<sup>&</sup>lt;sup>82</sup> Jane Rosengrave, 'You Only Live Once!' < <a href="https://www.19stories.org/copy-of-story-14-2">https://www.19stories.org/copy-of-story-14-2</a> [accessed 15 June 2020].

<sup>&</sup>lt;sup>83</sup> This point draws from Mason Marks work on algorithmic discrimination. Mason Marks, 'Algorithmic Disability Discrimination' (19 February 2019). Available at SSRN:

The EU's General Data Protection Regulation (GDPR), for example, protects sensitive personal information regardless of its source. Article 9(1) of the GDPR prohibits the processing of special categories of personal information, which include health and disability-related data, unless one of ten exceptions in Article 9(2) is met. Employment-based discrimination and 'vulnerability-based marketing' (ie. targeted marketing who are depressed and need a confidence boost, which I describe above at paragraph [34]) are also likely to fall foul of Article 9.

| sign here ▶ |                  |
|-------------|------------------|
| print name  | Dr Piers Gooding |
| date        | 25 June 2020     |





## **ATTACHMENT PG-1**

This is the attachment marked 'PG-1' referred to in the witness statement of Dr Piers Gooding dated 25 June 2020.

## **Curriculum Vitae**

## **Dr Piers Michael Gooding**

Research Fellow

#### Melbourne Social Equity Institute, University of Melbourne

I was educated at the University of Melbourne and Monash University. My scholarship is interdisciplinary and blends theoretical enquiry with applied qualitative research at the local, national and international levels. My main research interests are disability law and policy, international human rights law, the law and politics of mental health, and empirical legal research.

### **Education**

2010-2014 Doctor of Philosophy (Law)

Centre for the Advancement of Law and Mental Health, Monash University (incl. Visiting Fellow, King's College London, Dickson Poon School of Law). Supervisors: Prof Bernadette

McSherry and Prof Penelope Weller.

2003-2007 Bachelor of Arts with First Class Honours (History and Cultural Studies)

The University of Melbourne.

## **Awards and Scholarships**

| 2020    | Discovery Early Career Research Award, Australian Research Council.  |
|---------|--|
| 2019-20 | Mozilla Foundation Fellowship (2018-19).   |
| 2018    | Fondation Brocher Residency Fellowship, Brocher Centre, Geneva.  |
| 2014    | Vice-Chancellor's Commendation for Thesis Excellence (Law), Monash University.   |
| 2012    | Australian Bicentennial Scholarship, Menzies Centre for Australian Studies, King's College London: Six-Month Visiting Fellow, School of Law. |
| 2011    | The Dontas Family Travelling Fellowship (legal), 13 <sup>th</sup> <i>Greek/ Australian Legal and Medical Conference</i> , Kos, Greece.       |
| 2010    | Australian Postgraduate Award, Monash University (Law).  |
| 2008    | Australian Postgraduate Award, University of Melbourne (History).  |
|         |  |

### **Positions**

| Positions    |  |
|--------------|--|
| 2017-Current | Consultant, United Nations Economic and Social Commission Asia Pacific.  |
| 2018-Current | <b>Research Fellow</b> , Melbourne Social Equity Institute & Melbourne Law School, University of Melbourne.  |
| 2015-18      | <b>Postdoctoral Research Fellow</b> , Melbourne Social Equity Institute & Melbourne Law School, University of Melbourne.                                   |
| 2014-2015    | <b>Research Fellow</b> , Centre for Disability Law & Policy, National University of Ireland, Galway.   |
| 2013-2014    | <b>Research Associate</b> , University of Melbourne, supported by funding from the National Mental Health Commission, researching seclusion and restraint. |
| 2013         | <b>Research Associate</b> , Social Policy Research Centre, University of New South Wales, collaborating with People with Disabilities Australia.           |

- 2010-2013 **Research Assistant**, Centre for the Advancement of Law and Mental Health, Monash University, Faculty of Law.
- 2011-2013 **Tutor**, Monash University, School of Political and Social Inquiry ('Crime and Media') and Philosophy Department ('Human Rights Theory'); University of Melbourne, School of Social and Political Science ('Research Methods: Qualitative').
- 2008-2012 Research Officer, Victorian Mental Health Carers Network, advocacy organisation working in collaboration with the Victorian Department of Health and Human Services and the School of Psychiatry, University of Melbourne.

## **Publications**

#### **Book**

- 1. **P Gooding**, A New Era for Mental Health Law and Policy: Supported Decision-Making and the Convention on the Rights of Persons with Disabilities, Cambridge University Press (2017), in the CUP Disability Law and Policy series (281 pages).
- 2. F Beaupert, L Steele and **P Gooding** (Eds.), *Law in Context: Disability, Rights and Law Reform in Australia* (Federation Press, 2017) (152 pages).

## **Book Chapter**

- 1. **P Gooding** and R Kayess, 'Human Rights and Disability: An Australian Experience' in P Gerber and M Castan, *Contemporary Perspectives on Human Rights Law in Australia* (Thomson Reuters, 2020) (in production).
- 2. **P Gooding**, "Can Laws "Commit" Governments to Provide Mental Health Services? A Role for Human Rights in Securing Resources?' in S Okpaku (Ed) *Innovations in Global Mental Health* (Springer Nature, 2019) (in production).
- 3. C Roper and **P Gooding**, 'This is Not a Story: From Ethical Loneliness to Respect for Diverse Ways of Knowing, Thinking and Being' in E Flynn, A Arstein-Kerslake, C De Bhailis, M Laura Serra (Eds) *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories* (Routledge, 2018) 154-164.
- 4. **P Gooding**, "The government is the cause of the disease and we are stuck with the symptoms": deinstitutionalisation, mental health advocacy and police shootings in 1990s Victoria' in G Goggin, L Steele, and R Cadwallader (Eds.) *Normality and Disability: Intersections among Norms, Law, and Culture* (Routledge, 2018) 100–110.
- 5. **P Gooding**, A Arstein-Kerslake and E Flynn, 'Assistive Technology as Support for the Exercise of Legal Capacity' in D. Ferri and G. Giannoumis (Eds). *Fostering Accessible Technology through Regulation* (Routledge, 2017) 245-265.
- 6. **P Gooding**, B McSherry, A Arstein-Kerslake and S Mercer, 'Supporting Accused Persons with Cognitive Disabilities to Participate in Criminal Proceedings in Australia Avoiding the Pitfalls of Unfitness to Stand Trial Laws' in F Beaupert, L Steele and P Gooding (Eds.), *Disability, Rights and Law Reform in Australia* (Federation Press, 2017) 64-84.
- 7. **P Gooding** and S Quinlivan, 'Reasonable Accommodation' in A Pabsch and P Soderqvist, *UNCRPD Implementation in Europe A Deaf Perspective: Article 29: Participation in political and public life* (Brussels: European Union of the Deaf, 2015) 14-28.

#### **Peer-Reviewed Journal Articles**

- 1. **P Gooding**, B McSherry and C Roper, 'Preventing and Reducing "Coercion" in Mental Health Services: An International Scoping Review of English-Language Studies' (2020) *Acta Psychiatrica Scandinavica* (online first).
- 2. A Arstein-Kerslake, **P Gooding**, S Mercer, M Raymond and B McSherry, 'Implementing a Participatory Human Rights-Based Research Methodology: The Unfitness to Plead Project' (2019) 11(3), *Journal of Human Rights Practice*, 589-606. doi:10.1093/jhuman/huz034
- 3. **P Gooding**, 'Mapping the Rise of Digital Mental Health Technologies: Emerging Issues for Law and Society' (2019) 67 *International Journal of Law and Psychiatry* 101498 (Epub).
- 4. D Puras and **P Gooding,** 'Mental Health and Human Rights in the 21<sup>st</sup> Century' (2019) 18(1) World Psychiatry 42-43.
- 5. R McCausland, R Reeve and **P Gooding**, 'The Economic Case for Improving Legal Outcomes for Accused Persons with Cognitive Disability: An Australian Study' (2019) 15(4) *International Journal of Law in Context* 367-389.
- 6. M Lea, F Beaupert, N Bevan, D Celermajer, **P Gooding**, R Minty, E Phillips, C Spivakovsky, L Steele, D Wadiwel and P Weller, 'A disability aware approach to torture prevention? Australian OPCAT ratification and improved protections for people with disability' (2018) 24(1) *Australian Journal of Human Rights* 70-96.
- 7. **P Gooding**, 'The Right to Independent Living and being included in the Community: Lessons from the United Nations' (2018) 24 *International Journal of Mental Health and Capacity Law* 32-54.
- 8. L Brophy, V Edan, **P Gooding**, B McSherry, et al. 'Community Treatment Orders: Towards a New Research Agenda' (2018) 26(3) *Australasian Psychiatry* 299-302.
- 9. **P Gooding** and T Bennett, 'The Abolition of the Insanity Defense in Sweden and the United Nations Convention on the Rights of Persons with Disabilities: Human Rights Brinksmanship or Evidence it Does not Work?' (2018) 21(1) *New Criminal Law Review* 141-169.
- 10. M Simmons and **P Gooding**, 'Spot the Difference: Shared Decision-Making and Supported Decision-Making in Mental Health' (2017) 34(4) *Irish Journal of Psychological Medicine* 1-12.
- 11. **P Gooding,** J Anderson and K McVilly, 'Disability and Social Inclusion "Down Under": A Systematic Literature Review' (2017) 8(2) *Journal of Social Inclusion* 5-26.
- 12. **P Gooding**, A Arstein-Kerslake, L Andrews and B McSherry, 'Unfitness to Stand Trial and the Indefinite Detention of People with Cognitive Disability in Australia: Human Rights Challenges and Proposals for Change' (2017) 40(3) *Melbourne University Law Review* 816-866.
- 13. A Arstein-Kerslake, **P Gooding**, L Andrews, B McSherry, 'Human Rights and Unfitness to Plead: The Demands of the Convention on the Rights of Persons with Disabilities' (2017) 17(3) *Human Rights Law Review* 399-419.
- 14. **P Gooding**, S Mercer, E Baldry and A Arstein-Kerslake, 'Unfitness to Stand Trial: The Indefinite Detention of Persons with Cognitive Disabilities in Australia and the United Nations Convention on the Rights of Persons with Disabilities' (2016) 10 *Courts of Conscience* 6-18.
- 15. **P Gooding,** 'From Deinstitutionalisation to Consumer Empowerment: Mental Health Policy, Neoliberal Restructuring and the Closure of the "Big bins" in Victoria' (2016) 25(1) *Health Sociology Review* 33-47.

- 16. G Davidson, L Brophy, J Campbell, S Farrell, **P Gooding** and AM O'Brien, 'International Comparison of Legal Frameworks for Supported and Substitute Decision Making' (2016) 44 *International Journal of Law and Psychiatry* 30-40.
- 17. **P Gooding**, 'Navigating the Flashing Amber Lights of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns' (2015) 15(1) *Human Rights Law Review* 45-71.
- 18. **P Gooding** and E Flynn, 'Querying the Call to Introduce Mental Capacity Testing to Rights-Based Mental Health Law' (invited paper) in "Special issue Competency and Capacity: Issues Affecting Health Law, Policy and Society" (2015) 4(2) *Laws* 245-271.
- 19. **P Gooding**, ""…in a format that they can actually utilise meaningfully" Psychiatrists' Perceptions of Supported Decision-Making: A Victorian Empirical Study' (2014) 22(5) *Psychiatry, Psychology and Law* 701-722.
- 20. **P Gooding**, 'Change and Continuity in Mental Health Law: The Long Road to the United Nations Convention on the Rights of Persons with Disabilities' (2014) 20(3) *Web Journal of Current Legal Issues* 1-24.
- 21. B McSherry and **P Gooding**, 'Torture and Ill-Treatment in Health Care Settings: Lessons from the United Nations' (2013) 20 *Journal of Law and Medicine* 712-718.
- 22. **P Gooding**, 'Supported Decision Making: A Rights-based Disability Concept and its Implications for Mental Health Law' (2012) 20(3) *Psychiatry*, *Psychology and Law* 431-451.

## **Non-peer Reviewed Publications**

- 1. **P Gooding**, B McSherry, C Roper and F Grey, (2018) *Alternatives to Coercion in Mental Health Settings: A Literature Review*, Melbourne: Melbourne Social Equity Institute, University of Melbourne.
- 2. **P Gooding,** 'Housing First and the Maddening Myths of Homelessness' *Parity* (Council to Homeless Persons, October 2018).
- 3. **P Gooding,** 'The Forgotten 660,000 locked out of home ownership', *The Conversation*, 31 March 2017.
- 4. **P Gooding**, L Fleming, J Watson, S Koritsas, C Cuzzillo, and N Hagiliassis, *Decision-Making Support: An Educational Resource for Legal Professionals Working with People with Disability* (Scope Australia, 2016).
- 5. B McSherry, **P Gooding**, A Arstein-Kerslake and L Andrews, 'Disability-based disadvantage a life sentence?', *Pursuit*, Monday 4 April 2016.
- 6. L Andrews, A Arstein-Kerslake, **P Gooding** and B McSherry, 'New project to tackle the detention of Aboriginal and Torres Strait Islander people with disabilities', *Croakey*, 6 January 2016.
- 7. **P Gooding**, A Arstein-Kerslake, B McSherry and L Andrews, 'What Making a Murderer tells us about disability and disadvantage in criminal law', *The Conversation*, 9 February 2016.
- 8. **P Gooding**, 'Compulsory psych treatment in the home is ineffective, costly and violates human rights', *The Conversation*, 18 December 2015.
- 9. E Flynn and **P Gooding**, 'Warning over "assisted decision-making" plans in new Bill', *The Irish Times*, 19 June 2015.
- 10. P Gooding, 'Disability Services for the People, not the Market' Overland (online), October 2014.
- 11. **P Gooding**, 'Lars and the Real Issue' (on disability, mental health and human rights) *Big Issue*, Australia, syndicated on the Global Street News Press, 2012.

12. C Harvey, L Ning, R Callander, M Leggatt, **P Gooding** and S Woodhouse, *Privacy and Confidentiality Issues Paper* (Mental Health Council of Australia, 2009).

### **Submissions**

- 1. **P Gooding** and Y Maker, 'Submission to the Productivity Commission on its Draft Report on Mental Health', January, 2020.
- 2. P Gooding and Y Maker, 'Submission to The Victorian Royal Commission into Mental Health', July 2019.
- 3. **P Gooding**, 'Submission to the United Nations Advisory Committee of the Human Rights Council Questionnaire on new and emerging digital technologies and human rights', December 2019.
- 4. **P Gooding, (invited)** 'Submission to the Australian Guardianship and Administration and Council: draft guidelines on the participation of the proposed represented person in guardianship and financial management/administration hearings' January 2019.
- 5. Co-authored with colleagues from the Unfitness to Plead Project, Senate Committee Inquiry Commission on the Indefinite Detention of Persons with Cognitive and Psychiatric Impairment, 2018. In addition, I was invited by the Senate Committee to present oral evidence at its October 2017 hearing in Darwin.
- 6. **P Gooding**, S Mercer and Y Maker (submitted as part of the Unfitness to Plead Project), *Submission to the Royal Commission into the Protection and Detention of Children in the Northern Territory*, 28 October 2016.
- 7. A Arstein-Kerslake and **P Gooding**, Submission to the Committee on Bioethics (DH-BIO) of the Council of Europe regarding the Additional Protocol to the Convention on Human Rights and Biomedicine, 2015.
- 8. Co-authored Amicus Brief with colleagues from the PERSON Project, *Hadžimejlić et al v Bosnia and Herzegovina*, European Court of Human Rights, Application nos. 3427/13, 74569/13, and 7157/14.
- 9. L Steele, F Beaupert, and **P Gooding**, Submission to the Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (2014).
- 10. **P Gooding** and C Nicholson, Submission to the House of Lords Select Committee on the Mental Capacity Act 2005 (2013).

#### **Select Presentations**

- 1. (Invited) 'Advocacy and Research for Psychosocial Disability, Mental Health and Inclusion', AIDRAN Biennial Conference on Diversity and Disability Inclusion in Asia (ICDDA), Faculty of Law Brawijaya University, Indonesia, 24-25 September 2019.
- 2. 'Personhood, Ableism and the Memory of Aktion T4'
  - a. Australasian Association of Holocaust Organisations (AAHO), Conference to be held at the Sydney Jewish Museum, 22-23 September 2019.
  - b. Public workshop: "The Legacy of the Nazi persecution of people with disabilities", Jewish Holocaust Museum, 9 December 2018 (convenor).

- 3. 'Regulating the Revolution: The Risk, Hype and Promise of Digital Mental Health Care', Digital Citizens Conference, New Technologies: Rights, Responsibilities and Regulation, Melbourne Law School, 24-26 July 2019.
- 4. (Invited) 'Supported Decision-Making: A New Era for Mental Health Law', Indian Law Society as part of the Global Mental Health and Human Rights Summer School, Pune, India, October 2018.
- 5. (Invited) 'Supported Decision-Making: A New Era for Mental Health Law', The Victorian Mental Health Tribunal, Australia, April 2018.
- 6. (Invited) 'Supported Decision-Making: A New Era for Mental Health Law', Office of the Public Advocate, Victoria, Australia, March 2018.
- 7. 'Support Reinvestment' Shifting Mental Health Resources from Coercion to Rights-based Support, *Law and Society Conference*, Toronto, Canada, 2018.
- 8. 'Co-locating disability support workers in community legal centres: the findings of a 2-year action research project', *The Australian Social Policy Conference*, Sydney, September 2017.
- 9. 'People with Cognitive Disabilities in the Criminal Justice System: Addressing the Legal Barriers and Creating Appropriate Alternative Supports in the Community', *Reintegration Puzzle Conference*, 2017.
- 10. (Invited) 'Voices of Individuals Collectively Exploring Self-Determination', European Research Council Funded Project, National University of Ireland Galway, January 2017.
- 11. (Invited) 'Unfitness to Plead and Indefinite Detention of People with Cognitive Disabilities in Australia,' Testimony at the Australian Senate Standing Committee on Community Affairs References Committee, Inquiry into the indefinite detention of people with cognitive and psychiatric impairment, 2016.
- 12. 'Unfitness to Plead and Indefinite Detention of People with Cognitive Disabilities in Australia', *Reintegration Puzzle Conference*, Melbourne, 2016.
- 13. (Invited) 'Supported Decision-Making: From Theory to Practice', Irish College of Psychiatrists, professional development seminar series, Dublin, 2015.
- 14. (Invited) 'Supported Decision-Making: What Relevance to Social Workers?', Commissioned by the Czech Republic Department of Social Services, Prague/Brno, 2015.
- 15. (Invited) 'Global innovations in mental health law and policy from a human rights perspective: lessons from down under', Irish Mental Health Commission, Dublin, 2015.
- 16. 'The Evolution of Legal Capacity and Disability Justice in Australia', LIRC Disability at the Margins: vulnerability, Empowerment and the Criminal Law, Wollongong University, 2013.
- 17. 'Supported decision making: what does it mean for me?' 14 th Victorian Collaborative Psychiatric, Nursing Conference, 2013.
- 18. (Invited) 'Deinstitutionalisation and Supported Decision-Making Law Reform in Victoria', Regulation Quality Improvement Authority, Government of Northern Ireland, Belfast, 29 May 2012.
- 19. 'Supported Decision-Making: A New Era for Mental Health and Disability Rights?' *Law, Medicine and the Public Good,* 13<sup>th</sup> *Greek/ Australian Legal and Medical Conference,* Greece, June 2011 (prize award).

### **Editorships**

• Co-Editor, *International Journal of Law and Psychiatry*, 'Special Issue: Psychiatry and Law in the Digital Age: Untangling the Hype, Risk and Promise' (in production).

- Co-Editor, *International Journal of Mental Health and Capacity Law*, hosted by the University of Northumbria; Editor-in-Chief, Kris Gledhill (ongoing).
- Co-Editor, *Law in Context*, 'Special Issue: Disability, Rights and Law Reform in Australia', Federation Press, La Trobe University (2017).

### **Recent Media Appearances**

- <u>'Man suffering from brain injury locked in jail, with no end in sight'</u> (2019, November 15) *The Age, Sydney Morning Herald, WA Today* and *Brisbane Times*
- 'NDIS plan to reduce delays only a stopgap, disability advocates say' (2019, June 26) The Guardian
- 'Australians with life-threatening swallowing condition win NDIS battle' (2019, June 14) The Guardian
- 'Gross miscarriage of justice': unfit to plead but still locked up' (2017, September 12) The Age, Sydney
  Morning Herald
- 'Cognitively impaired man jailed for ten years without trial calls for reforms' (2017, September 12) SBS
  Online

## **Memberships and Affiliations**

#### Current:

- Member, National Disability Services Victoria Research Advisory Group.
- Member, Australian Supported Decision-Making Network.
- Member, Australian and New Zealand Association of Psychiatry, Psychology and Law.
- Member, Advisory Panel, *Mental Capacity Act: Stories of Intention: Welcome Trust Fund Project* (UK), Dr Lucy Series (CI), Cardiff University, School of Law.

#### Former:

- Member, Advisory Board, Disability-specific forms of deprivation of liberty, Centre for Disability Law and Policy, National University of Ireland, Galway (2018-19)
- Member, Disability Reference Group, Vic Equal Opportunity and Human Rights Commission (2017-18)
- Member, Advisory Panel, VOICES Voices of Individuals Collectively Exploring Self-Determination (European Research Council Project) (2015-17)

#### **Teaching**

| 2018-20 | University of Melbourne, Melbourne Social Equity Institute (MSEI) & Law School – MSEI Doctoral Academy; Criminology; Disability Breadth Subject Co-ordinator (Doctoral Academy), Guest Lecturer (3 <sup>rd</sup> Year Criminology and Disability Studies) |
|---------|---|
| 2017    | Monash University, Masters in Health and Human Rights  Guest Lecturer   |
| 2016-17 | University of Melbourne, Disability Human Rights Clinic; LLM thesis marking Guest Lecturer, Student Supervision, Thesis Marking   |
| 2016    | University of Melbourne, Health and Human Rights, Nossal Institute  Guest Lecturer  |

| 2014-16 | National University of Ireland, Galway, Masters in International Disability Law and Policy  Curriculum Advisor, Guest Lecturer |
|---------|--|
| 2011-14 | University of Melbourne and Monash University (Human Rights Theory, Crime and Media, and Research Methods)                     |
|         | Tutor  |

## Reviewing

I have been invited to review journal articles submitted to publications such as: *The Lancet* (ISSN 0140-6736); *Dublin University Law Journal* (ISSN 0332-3250); *Punishment and Society* (ISSN 1462-4745); *The International Journal of Law and Psychiatry* (ISSN 0160-2527); *Journal of Policy and Practice in Intellectual Disabilities* (ISSN 1741-1130); *Scandinavian Journal of Disability Research* (ISSN 1501-7419); *Australasian Psychiatry* (ISSN 1440-1665); *Chronic Illness* (ISSN 1742-3953); *American Journal of Orthopsychiatry* (ISSN 0002-9432); and *Laws* (ISSN 2075-471X).

#### Volunteer

- Board Member, COM, Belonging Matters, disability advocacy NGO, 2012-2019.
- Community Visitor, Office of the Public Advocate, Victorian Government 2011-16.
- Chair, Higher Degree Research Student Body (Law), Monash University, 2013.

NOTE: Supporting documents for any of the above are available upon request.