Submission to the Productivity Commission Inquiry into Mental Health, A Human Rights Perspective

By the Mental Health Coalition of South Australia (MHCSA) and the Lived Experience Leadership & Advocacy Network

Contents

Submission overview

People with lived experience of mental health issues who have been significantly impacted by their experiences are at the heart of our work. Those who shared their experiences and insights, which included people with lived experience as well as workers from the non-government sector, hold a strong belief that mental health services as currently constructed are deeply flawed and that significant improvement is required to better support people to achieve the full rights of citizenship. They also propose that the human rights issues facing people with mental health issues, particularly those more severely impacted by mental illness, must be better addressed.

This submission has been written by the Mental Health Coalition of South Australia (MHCSA) and the Lived Experience Leadership & Advocacy Network (LELAN). It builds on broader work of these organisations, Carers SA and Health Consumers Alliance of South Australia (HCASA) have been doing in the area of human rights and mental health in South Australia.

The Mental Health Coalition of SA is a peak body with a mission that all people in SA will get access to the mental health support they need when they need it.

LELAN is an emerging organisation in South Australia that is *by*, *for* and *with* people with lived experience of mental health issues, including those with personal lived experience (consumers) and those that support, care for or are allies.

Methodology

This submission is informed by the following activities:

Consultation forum

A two-and-a-half-hour forum was held for people with lived experience and mental health services in late March. The session had four components:

> 1. exploring a shared understanding of 'recovery' given it's complex and often misrepresented or co-opted definition within policy and planning processes
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> 2. identifying the enablers for better upholding the human rights of people with mental illness within mental health services given the difficulty in navigation of the system and the known harm that many people experience when accessing care and treatment
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> 3. prioritising suggested question areas from the Issues Paper that mattered most to people who were in attendance. The areas chosen to dive deeper into were: the Productivity Commission assessment approach; structural weakness; health workforce; justice; education and training; and coordination and training
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> 4. each person sharing their response to *'the most important thing for the productivity commission to know'*

Survey

An online survey. Questions are in Appendix 1.

In August 2018 a breakfast event with a lived experience guest speaker, who is a Human Rights Advisor in an interstate Consumer organisation, was held on the morning of a national mental health conference in Adelaide. This was followed by a Human Rights & Mental Health Workshop in November 2018 that was attended by over 50 people. This session focused on the key enablers for human rights to be upheld, people's hopes for action and ideas for moving forward in South Australia to address this topic.

Understanding recovery and people's experience

We urge the Productivity Commission to take particular care with the assumptions that underpin most mental health system analysis work and ways of understanding people who experience mental health issues. This is particularly important in regards to how people's experiences are defined and labelled, how recovery is understood, the particular use of language and potential value judgements of people when words such as 'productivity' and 'burden of disease' are used.

The invitation for care and reflection with these areas is particularly relevant to understanding the broader 'costs' related to mental health issues and grappling with determining 'how people can be enabled to reach their potential in life, have purpose and meaning, and contribute to the lives of others' which is core to the Productivity Commission's Inquiry into Mental Health overall.

Comprehensive understanding of the concept of recovery and how to support people to achieve this has not been well understood or supported by the mental health system. Enabling recovery and supporting the self-determination of people with mental health issues are fundamental to people's purposeful and meaningful involvement in communities and society. Consideration should also be given to peoples' reported experiences of mental health issues and illness not having solely negative impacts for how they choose to live and the relationships and opportunities that emerge as people progress in their recovery.

The recovery process is different for each person but the outcomes are broadly similar, encompassing things such as decent housing, good relationships, meaningful activity and more. The opposite of these recovery benefits are the very things that the people we consulted with identified as the 'non-monetary costs' of mental illness; *lack of opportunity*, *feeling isolated*, *struggling with personal connections*, *diminished voice and rights*, *sense of guilt for not being able to access appropriate and adequate care options due to lack of money – shame*, *homelessness is a major concern* and *just wanting to talk to someone who can help that won't cost an arm and a leg*.

Recovery is a holistic concept affecting all domains of life. For people more severely impacted by mental illness, good clinical care is often a very small part of the recovery process but takes up over 90% of the mental health spend. There is a lot of emphasis in mental health regarding the 'evidence base', however our consultation contends that much of this is too narrowly focused on medical and clinical approaches with minimal resources provided to explore alternative and preferred options of support that people with lived experience want access to. We urge the Productivity Commission to prioritise developing a holistic program logic to underpin the analysis and recommendations regarding good investment in mental health. The human rights view of mental health identifies the need to invest more in non-clinical supports to provide a more balanced system and there is strong evidence to show the effectiveness of this.

When people with lived experience of mental health issues and professionals who support them were asked what recovery means and looks like, thus how people are enabled to live meaningful and contributing lives, they shared the following. The need for fundamental recognition that people have the *right to define their own experience* rather than the mental health system defining it for them, that people with mental health issues *deserve what you've got but may need extra consideration to get there* and that others have a role in *help[ing] us address the issues that stop us having the same rights*. They propose that the *ethics, policy and legislative frame needs to support recovery,* that *mental health literacy needs to be tuned to human rights* through changed *language and beliefs* and the need for *human rights treaties to have an impact in mental health*.

In response to what helps people with mental health issues one survey respondent provided this summation, *for people to encourage, support and 'see' the person beyond their illness. Inclusion (true inclusion) in all areas of life regardless of 'disability', but based on ability. Consultation on interests, aspirations and 'real options'*.

The responses indicate that recovery is not a simple concept and does not land solely on the shoulders of people who experience mental health issues or provide frontline support to them. Conceptualisation, environmental and systemic changes are required for it to be realised and available to all people with mental illness.

Key enablers for improving outcomes for people with mental health issues

As a part of the consultation to inform this submission we asked people about the key enablers for better upholding the human rights of people with mental illness and whether they were currently present in support offered to people. Enablers identified at a prior workshop, attached in Appendix Two, were shared to prompt thinking. People with lived experience of mental health issues told us, without hesitation, that the current way that mental health systems and services are constructed are a long way from delivering the environment or results that people want and need for recovery.

Key enablers identified were:

A values-based approach is essential

The values of hope, responsibility, mutuality and reciprocity, authenticity, egalitarian approach and empowerment of people with lived experience of mental health issues are essential to any approach. When these values are not held, labels and practices that disempower people, diminish recovery efforts and remove people's rights are more present.

Recognising, valuing and utilising people's lived experience

This was about positioning people with lived experience as having *expert* knowledge (*'we know s#*t too'*) that must be listened to, the need to a*cknowledge people's unique skills, resources, value* and embracing the evidence that *lived experience brings agency and resilience as well as recovery*. In addition to these aspects of lived experience an enabling factor is changing the culture of mental health understanding and approaches to make space for grass roots involvement of people with lived experience and allowing any person with lived experience *to be part of the movement* for change and better lives.

Acknowledging the impact of trauma on people's mental health

The link between trauma and mental illness is strong and should be a driver of more targeted and better supports for people. When a trauma-informed approach underpins service provision there is greater sensitivity to the individual needs of people, recognising that everyone has different backgrounds and experiences that impact their ability to function and recover.

A focus on equity and the social determinants of health

A social model of care and considering the social determinants of health must factor into decisions and investments that are made for mental health, particularly as a first response and early in people's mental illness journey. A holistic approach leads to a system that collaborates, is connected and provides the support and interventions that meet people where they are at.

Transparency in reporting (regularly)

Having mechanisms in place to support the reporting of measures related to human rights is a way to increase public awareness and accountability of services. It is proposed that systems to monitor human rights across a range of areas, for example mental health, housing, education, etc will be useful.

People want those experiencing emotional distress and mental health issues to not be stigmatised for their experiences, seen as different or 'othered' and to be able to easily access help when they need it, just like when they have a physical illness.

The enablers and views from our consultation could be used to develop a 'Human Rights Lens' through which the Productivity Commission could identify and assess the transformational value of proposed new investments or re-deploying existing investments. This should be with a preference toward expanding investment in psychosocial supports. Greater recognition is required of the lived experiences of people with mental health issues and the role that co-design can play in driving change and better outcomes.

The National Mental Health Commission's concept of a 'contributing life' is insightful in describing what a good life looks like and is based on extensive consultation with people with lived experience. We urge the Productivity Commission to approach their Inquiry not from an illness paradigm, but from the human rights perspective of aiming for and expecting to achieve equality in enjoyment of the full rights of citizenship. This is more than a reductionist view of welfare that aims to help people be a little less destitute. It will require clear thinking about the program logic of how to support people to achieve a contributing life. For people more severely impacted by mental illness, it will require a more holistic approach than the current dominant focus of ameliorating the clinical impacts of mental illness. This is not an argument against good clinical care, it is an argument that people with more complex needs require more than just good clinical care to enjoy their human rights fully.

Priority inquiry questions and responses by the people we consulted with

Regarding the Productivity Commission's assessment approach

When discussing the assessment approach of the Productivity Commission people called for a broader more holistic approach to be taken. In addition to analysis of spending measures or employment figures our consultation highlighted the need for a broad view of social inclusion to be used. This was expressed as focusing on social return of investment in mental health rather than social spend. Using measures of effectiveness based on the social determinants of health were suggested.

For people with lived experience *outcomes based on hope, healing and recovery*[1], that *look at strengths as well as needs* and measures related to quality of life are critically important. They also highlighted the necessity of people with lived experience being involved in the co-design and transparent use of any measures that are used.

Participants also raised how important it is to account for the fact that current 'help' provided by services sometimes contributes to harm for people with mental health issues.

Regarding structural weakness

The biggest structural weakness identified as something that *needs to end* is the over focus on hospitals and beds that *suck up the majority of funding*. People want funds redirected to wrap around supports after hospital stays to prevent readmission, investment in identifying at risk groups and removing access barriers to care related to inclusion and exclusion criteria. The dominance of psychiatry and the siloed nature of service delivery and funding were noted as barriers to quality, holistic and easy to navigate services. This was seen as problematic across departments and jurisdictions.

Participants suggest a move toward early intervention, flexible individualised care and support. Improvements in clinical care through collaborative identification of issues and solutions between people with lived experience and clinicians were identified as key strategies moving forward. One solution shared was to *open up the system for people to reach out early and self-identify what help is needed*. Other proposals were for 'social prescribing' and lived experience run solutions to be explored further.

Regarding the health workforce

The skills, knowledge and competency of all people within the health workforce can be strengthened. Education regarding recovery, human rights, compassionate listening approaches and embracing diversity should be standard. Practices and structures supporting positive work environments, supervision and for integrating with other services and systems should also exist. The attitudes and values of workers, that

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[1] Note that in this section the words in *italics* are direct quotes from our consultation.

people *can do the job in the right way*, were also highlighted as making a difference for how care and support is provided.

The inclusion, expansion and development of the peer workforce – consumers and carers – was proposed by participants. Suggestions included the need for more roles, career pathways, flexible work arrangements and a national strategy to support professional recognition and standards development. Promotion of the benefit of peer workers to consumers and carers as well as with clinicians and service leaders will support its growth and acceptance as a valuable resource. People want *workforce planning that values and sees the peer workforce as integral to the team rather than 'nice to have'*.

Participants spoke about the importance of changing hierarchical structures within mental health care that places power, authority and control predominately with Psychiatrists. People would prefer a reallocation of funds to lived experience workforce, social inclusion work and greater *equity across the workforce*.

Regarding justice

Key areas prioritised in our consultation for providing better outcomes in the justice system were: Diversion programs; improved in-reach of mental health supports to prisons; better integration of services post-release to include employment, social support and housing needs; growing a specialised peer workforce of people who have been in prison; and better recognition of the impact of trauma from earlier in life. This would require a shift *to emphasise that they are a health service not a containment / control service* and develop a *focus on reform and rehabilitation rather than punishment*.

Regarding education and training

Participants proposed changes to school, university and teacher curriculums to include human rights and *mental health literacy at every level*. Understanding the impact of Adverse Childhood Experiences, bullying and establishing trauma-informed learning environments are essential.

In addition to broadening teacher education, increasing the number of education staff with specialised mental health training, who may or may not be teachers, is encouraged. This may include the employment of social workers, counsellors, other professionals and peer workers or creating better pathways for the in-reach of mental health specialist skills and services into school settings.

Alternative education programs and re-entry programs are vital to the ongoing education of people at all stages of their learning and education journey.

Regarding coordination and integration

Coordination and integration are the key to providing high quality, safe and effectives services. People with lived experience want and deserve *an integrated system that is 'owned' by all stakeholders equally*, that

sees the whole person and offers a variety of supports. It is not enough just to prioritise better coordination and integration of clinical services. Non-medical model approaches and new ways of supporting people, such as Open Dialogue and Hearing Voices approach, that have proven effective in other jurisdictions yet may not have enough research completed to be considered as 'evidence-based' must be considered. We need to create a system and services that ask, '*what is needed for and with this person and how are we going to get it?*'

People want mental health services to have good governance, be accountable and have clear processes for feedback and action. The culture of services is seen as a current barrier that stifles coordination and integration, particularly across sectors and with other social services – such as housing.

Human rights and mental health: What we know and what we can do about it

Mental Health is underfunded overall and people more severely impacted are struggling

There is a lot of criticism of mental health services and system design but a fundamental barrier to a quality and effective mental health system is an appropriate level of funding. Mental health is underfunded within the health spend relative to the disease burden caused by mental illness. This is not controversial, has been known for a long time and needs to be adjusted. We urge the Productivity Commission to recommend a 50% increase in mental health expenditure and also to ensure that this increased spend delivers on the human rights agenda in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD advocates a move from a medical to a social model of mental health for people experiencing mental health issues, particularly the consumers and carers with severe and enduring experiences. Our consultation with people with lived experience and UN Reports[2] highlight frustration with the lack of progress in investing in more holistic social models of mental health.

State systems need better human rights emphasis

The WA Mental Health Commission analysed their mental health spend using the National Mental Health Services Planning Framework (NMHSPF). They found underspends in all areas of mental health services from hospital beds, community mental health services (mostly clinical and mostly delivered by teams employed by the Department) and community support (mostly psychosocial rehabilitation type services and mostly delivered by mental health NGOs). Interestingly, their findings showed that whilst unmet need in inpatient settings was around 20%, unmet need was over 70% in community support[3].

The WA Commission expressed this as an unbalanced system and a significant part of their strategic plan was to increase the relative investment in community support. This will build on their investment in clinical support as people get more psychosocial support to better manage their illness and resolve issues that have arisen in their lives. There is strong and growing evidence for the effectiveness of psychosocial supports in supporting people to lead better lives and reduce their reliance on unplanned acute care. Some examples of independently evaluated psychosocial support programs in SA are Intensive Homebased Support Services (IHBSS) and Crisis Respite. The evaluators of IHBSS estimated that it would more than pay for itself in terms of the cost-offsets of reduced hospitalisation for those supported in the service. Crisis respite provided a psychosocial support alternative to emergency department presentation for people in crisis or at risk of moving into crisis. It was delivered either in a small 20 bed centre or could outreach support to an individual's home[4] [5].

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[2] UN Human Rights Council (2017). Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. A/HRC/35/21. Accessed via https://www.un.org/en/ga/search/view_doc.asp?symbol=A/HRC/35/21

[3] Western Australian Mental Health Commission (2015). Better Choices. Better Lives. Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015–2025. Perth, Western Australian Mental Health Commission. Accessed via www.mhc.wa.gov.au/media/1301/the-plan_final.pdf p.20.

[4] Zmudzki, F., valentine, k., Katz, I., Loebel, A., & Bates, S. (2015). Evaluation of Intensive Home Based Support Services for SA Health (SPRC Report 03/2015). Sydney: Social Policy Research Centre, UNSW Australia. Accessed via www.sprc.unsw.edu.au/media/SPRCFile/1_SPRC_Report__Evaluation_of_Intensive_Home_Based_Support_Services_v2.pdf

[5] Zmudzki, F. Griffiths, A., Bates, S., Katz, I., Kayess, R. (2016). Evaluation of Crisis Respite Services: Final Report (SPRC Report 06/16). Sydney: Social Policy Research Centre, UNSW Australia. Accessed via www.sprc.unsw.edu.au/media/SPRCFile/Crisis_Respite_Services_Evaluation__Final_Report.pdf

One mechanism that the Productivity Commission could consider to achieve better human rights outcomes is to review approaches to Commonwealth – states funding agreements in health and mental health to deliver a better balance of support options from hospital-based to community support. The current KPIs should be expanded to include a much greater focus on social and health outcomes in line with our human rights obligations. This is expressed in the concepts such as recovery, accessing the full rights of citizenship and the National Mental Health Commission concept of a contributing life[6].

There is a strong view within health and mental health that such things are beyond the responsibility of a health system which should prioritise clinical outcomes. That view is dated and will not lead to the outcomes people with lived experience say they want. For people with complex needs it is not sufficient to deliver full human rights under our international treaty obligations.

We need to achieve progress in areas such as housing, physical health, education and training, employment, income, social and recreational activity etc. The Living in the Community Questionnaire has been developed by Mental Health Information and Strategy Standing Committee (MHISSC)[7] and could be used as a tool by service providers to measure progress in some of these key areas.

Current models of psychosocial support show excellent value for money in terms of supporting people to build better lives in the community and reduce reliance on hospital care[8]. The use of more human rights based KPIs should drive better models and more innovation to deliver better human rights outcomes in areas where progress is slow. In this context, psychosocial supports should be viewed as a bridge to more support outside of health and mental health where required.

The investment in mental health currently across all jurisdictions is overwhelmingly focused on medical approaches to crisis. Less than 10% is spent on NGO delivered psychosocial supports and the pathways in some states is not timely. For example in SA access to most psychosocial supports is via referral from Community Mental Health teams. A human rights approach would argue for easier and more direct access pathways to psychosocial supports for individuals. Increased capacity for psychosocial supports to support people in crisis is an important step to reducing reliance on emergency and crisis mental health care.

Housing is a priority

Our consultation highlighted housing as an important priority that requires urgent attention. Key issues are: not enough access to public and community housing; cost of private rental; insecurity of tenure in private rentals; need for support for some people to access and maintain tenancies. The issues of support should be addressed in recommendations to increase psychosocial support but we urge the Productivity Commission to consider how to increase access for people more severely impacted by mental illness to safe, affordable, stable and appropriate housing stock. There have been a number of studies showing that this will lead to a significant reduction in use of bed based mental health services and it is also a key

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[6] National Mental Health Commission. (2014). Contributing Lives, Thriving Communities - Report of the National Review of Mental Health Programmes and Services. Accessed via www.mentalhealthcommission.gov.au/our-reports/our-national-report-cards/2014-contributing-lives-review.aspx

[7] Living in the Community Questionnaire (LCQ). Accessed via www.amhocn.org/special-projects/living-community-questionnaire-lcq

[8] Community Mental Health Australia (CMHA: 2012). Taking Our Place — Community Mental Health Australia: Working together to improve mental health in the community. Sydney: CMHA. Accessed via https://cmha.org.au/publications/

element of human rights[9]. AHURI provide a good summary of the issues and provide policy recommendations across mental health and housing[10]

Recommendation 1: States and the Commonwealth need to invest at least 50% more in mental health to match the burden of disease.

Recommendation 2: Use a human rights approach as a lens to assess new investments in mental health, including a strong focus on the 290,000 people with complex support needs.

Recommendation 3: Review and recommend changes to the relevant Commonwealth states funding agreements to sharpen the human rights focus of state mental health systems including additional KPIs that prioritise recovery. Service innovation funding should prioritise increasing the capacity of psychosocial supports to provide crisis support as an alternative to Emergency Department presentations.

Recommendation 4: Review Commonwealth States housing agreements and other options to increase access to safe, affordable, secure, stable and appropriate housing for people impacted by mental illness.

The NDIS needs significant improvement for people with psychosocial disability

The NDIS targets approximately 65000 of the 2900000 Australians with mental illness and complex support needs[11]. This means that a relatively small number of people will be accepted into the Scheme and that psychosocial supports must be available outside of NDIS for those not eligible.

The defunding of a range of Commonwealth and state/territory mental health services delivered by NGOs as part of the bilateral agreements represents one of the worst mental health policy decisions ever made in this country.

The disability support needs for people with primary psychosocial disability have not yet been properly considered in the Scheme, resulting in it being deeply flawed in terms of delivering on expectations.

Work completed by Mental Health Australia highlights a need to redesign plan elements[12]. Our submissions to various NDIS inquiries highlight that some plan elements such as core supports, despite recent increases

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[9] Commonwealth Government 2004. Senate Select Committee on Mental Health- 'A national approach to mental health – from crisis to community - Final Report' Chapter 8 eg 8.22 for SA. Accessed via https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Former_Committees/mentalhealth/report/c08

[10] AHURI 2018. Housing, homelessness and mental health: towards systems change. accessed at https://www.ahuri.edu.au/__data/assets/pdf_file/0023/29381/Housing-homelessness-and-mental-health-towards-systems-change.pdf

[11] Mind 2017. Response to the Joint Standing Committee inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition. Accessed at https://www.mindaustralia.org.au/sites/default/files/Response_to_JSC_inquiry_into_the_provision_of_NDIS_services.pdf

[12] Optimising Psychosocial Supports Project by Mental Health Australia. Accessed via mhaustralia.org/media-releases/optimising-psychosocial-supports-project-report

in price, are not priced highly enough to enable organisations to employ people with specific skills and experience relevant to supporting people with mental illness[13]. Even with a higher hourly rate, this approach is likely to save money over the longer term as people are supported to build more skills and require less support. The $1.6b lower projected expenditure for NDIS in 2019-20 indicates in part, that the funding is there to implement this approach.

Family carers report the NDIS as being stressful and time consuming to interact with the NDIS. This is disappointing and we are receiving feedback from aging carers citing frustration. Family carer roles need more consideration within NDIS for people with primary psychosocial disability, especially where they are providing significant support already.

Lived experience roles have not been adequately defined for psychosocial disability and with the demise of PHaMs it is possible that skilled, qualified and experienced lived experience workers will be lost to mental health and disability.

Feedback from people applying for support via NDIS report it to be time consuming and stressful. The concept of compelling people to emphasise how disabled they are to receive service is deeply flawed in terms of human rights and recovery approaches in mental health.

Recommendation 5: The Productivity Commission consider improvements to NDIS for people with psychosocial disability and their families particularly with regard to:

- Plan elements suited to developing and delivering competent psychosocial disability support plans

- Hourly rates for plan elements that ensure appropriate skills, knowledge and experience can be provided by service providers

- Better integration of family carer knowledge and needs into the planning and service delivery process

- Define roles to enhance choice regarding access to qualified lived experience support workers

- Revising entry pathway to reduce the need for people to emphasise the disabling impacts of their illness.

Commonwealth systems

The current range of Commonwealth investments appear to lack coherent program logic in terms of delivering recovery results for people more severely impacted by mental illness. There is currently an enormous amount of work underway, including under the auspices of the 5th National Mental Health and Suicide Prevention Plan[14], on improving clinical systems and care. This is welcome, but the human rights

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[13] (eg http://www.mhcsa.org.au/submission-parliamentary-joint-standing-committee-ndis-market-readiness/mhcsa-submission-parliamentary-jsc-ndis-market-readiness-0218/

[14] Commonwealth of Australia. (2017). Fifth National Mental Health and Suicide Prevention Plan. Department of Health : Canberra. Accessed via apo.org.au/sites/default/files/resource-files/2017/10/apo-nid114356-1220416.pdf

approach shows that it is ultimately too narrowly focused to deliver the more holistic outcomes required. Reports by the UN in 2017 highlight that Australia has a long way to go to embed a human rights approach into mental health services. We urge the Productivity Commission to recommend that any major new Commonwealth initiatives be tested against this yardstick[15][16].

Equity for disadvantaged groups is poorly addressed in Medicare and PBS systems. There are some PHN initiatives aimed at increasing equity of access to clinical care. In other areas, there are significant disinvestments such as PHaMs, PIR, D2D Living and MHR:CS that will increase the inequity for people with more severe mental illness. The impending demise of these programs represents the biggest step backwards in 25 years of mental health reform that has aimed to increase community supports. As argued above, NDIS aims to provide support for 65 000 people and the demise of Commonwealth mental health programs will reduce options for the 225 000 or so people with complex needs outside of NDIS.

The loss of capacity in Commonwealth mental health programs outside of NDIS will lead to more people needing to access acute and crisis care. These programs were designed to solve particular problems in the mental health systems and, with the demise of these programs, those problems will re-surface. A key feature of PHaMs that will be greatly missed is the ability for quick access and for anyone to refer to the program, including GPs, family, self-referral. Loss of PHaMs means that people on waiting lists to access other services will no longer be able to count on PHaMs support to help avert crisis. The problem-solving approach of Partners in Recovery will also be missed.

We urge the Productivity Commission to look at mechanisms for providing the psychosocial support needs of the 225 000 people outside of the NDIS. This investment must have a human rights based program logic driven by recovery focused KPIs (measured at least initially using the Living in the Community Questionnaire (LCQ)). Consumer and carer experience of service surveys are also essential.

Initially the current models could be expanded and extended whilst the KPIs are established and data collected. Then models can be continuously improved based on data and using a co-design process dominated by lived experience input. The risk of not doing this is the continuation of high usage levels from this cohort of a wide range of emergency, acute, justice, welfare and social services.

Another risk raised strongly in our consultation is the impact of lack of alternatives to clinical care and the impacts of medications, particularly anti-psychotics, on people. One of our participants provided information and references on negative impacts of medications and alternative approaches to delivering clinical services such as Open Dialogue and Soteria House. (This is included in full in Appendix 3)

Associated with the lack of availability of psychosocial supports to people with complex needs is a health and mental health system where clinicians are time poor. There are various studies showing high rates of prescribing in Australia and high rates of Community Treatment Orders. Currently only a small percentage of psychosocial support needs are met for people with complex support needs which contributes to the pressure on the clinical systems and limited clinical time. Effective psychosocial supports at scale, will reduce reliance on emergency and acute care as people get support to better manage their illness and build a better life in the community. This will make the clinical investment more efficient as GPs, for example, are able to do less crisis mental health care and more physical health care. It is also likely that an increase in GP confidence in the availability and effectiveness of psychosocial supports could reduce prescribing of medications.

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[15] Report of the United Nations High Commissioner for Human Rights. (2017). Mental Health and Human Rights. Accessed via www.lelan.org.au/wp-content/uploads/2019/04/Special-Rapporteur.pdf
[16] Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Accessed via www.lelan.org.au/wp-content/uploads/2019/04/MH-HR.pdf

The Report 'People living with psychotic illness in Australia' has an excellent overview of issues and good insights specific to psychosis[17]. It is particularly helpful because it is from a survey of people living with psychotic illness. Table 15-2 highlights the side effects reported by survey respondents. Table 15.1 reports benefits of medications with 57% saying it had a lot of relief from symptoms with 38% responding that they only got a little or no relief. Table 17.4 is useful in highlighting that the key challenges faced by individuals. The list included some illness related issues such as managing uncontrolled symptoms but most were psychosocial related issues like social isolation, employment, financial needs.

> Recommendation 6: That the PC recommend psychosocial support for the estimated 225 000 people who are not the target of the NDIS. Initially this should be continuation and expansion of existing Commonwealth mental health programs PHaMs, PIR, D2D Living and MHR:Carer Support. Continuous improvement to be based on developing KPIs and data collection focused on human rights outcomes. Key priorities including housing and employment.

Lived experience voice and structures that build momentum for achieving human rights progress

The current structures that dominate mental health systems are overwhelmingly based on medical models and the leadership and membership reflects that. The lack of peak consumer and carer bodies in a number of jurisdictions, including nationally, remains a significant gap.

The relevance of peak bodies for bringing the diverse voice of people with lived experience together was referred to by a survey respondent. *We need to make sure there are a variety of voices heard. Not just the shiny successful ones. Not just the flavour of the month ones. Respect needs to be given to all voices and to all approaches to managing health.*

The key reports on the Oakden scandal in SA were written by the then Chief Psychiatrist and the Independent Commissioner Against Corruption (legal expert). The vision for the voice of lived experience in future models of care is restricted to advising within the clinical governance framework[18]. The human rights considerations in such frameworks are limiting and focused on eliminating abuse. Whilst welcome, this approach to mental health care will fail to address the broader requirements of upholding human rights and the inclusion of people with lived experience at all levels of service planning, design, delivery, evaluation and governance.

For Mental Health Commissions to be truly effective they need more power to influence and also to ensure that they bring the voice of lived experience. Mental health commissions should be firmly focused on achieving progress on human rights and this requires a focus well beyond mental health and health.

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[17] Australian Government. (2011). People Living with Psychotic Illness 2010: Report on the Second Australian National Survey. Accessed via
www.health.gov.au/internet/main/publishing.nsf/content/717137a2f9b9fcc2ca257bf0001c118f/$file/psych10.pdf
[18] Groves A, Thomson D, McKellar D and Procter N. (2017) The Oakden Report. Adelaide, South Australia: SA Health, Department for Health and Ageing. Accessed at
https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/resources/oakden+report+final

> Recommendation 7: That Mental Health Commissions be established in each jurisdiction with a mandate to progress the human rights agenda, with a particular focus on severe mental illness.
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> That peak bodies for the lived experience voice be resourced in each jurisdiction to bring lived experience and human rights perspectives to mental health reform processes.
>
> That the human rights agenda sit with first ministers in each jurisdiction to reflect the broad collaboration required not just between jurisdiction abut across whole of government.
>
> Mental Health Commissions and lived experience peak bodies to be funded by and report to first ministers in each jurisdiction.

Mental Health Literacy

In health we have trained people to assume that if they have a problem, they go to their GP, get a pill and it is fixed. This narrative and approach does not work for complex issues, such as severe mental illness and Adverse Childhood Experiences, where the majority of the impacts do not have a quick medical fix.

The human rights view of mental health highlights that people not only need to work out how to manage their illness but also overcome barriers and associated challenges to build a good life in the community.

Approaches to mental health literacy need to move beyond stigmatising approaches to encouraging people to seek help from their doctor. This approach disempowers friends, family and the community if not balanced by messages that we all have a role and that other options for support are available. We also have to address negative stereotypes that remain pervasive, particularly in relation to the lower prevalence illnesses such as schizophrenia and bipolar disorders. Some of the key problems with current approaches to mental health literacy are outlined in this paper[19].

> Recommendation 8: That mental health promotion and literacy investments contain balanced messages that do not inadvertently increase stigma or devalue the important role of the person with illness and their family, friends and community.

Lived Experience Workforce

Our consultation resulted in strong feedback in all areas discussed that the role of lived experience in the workforce is a key driver of improved mental health services and supports, *I think everyone should have a lived experience mentor, somebody who just 'knows'*. There is a need to expand roles, specialisation,

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[19] Ashfield, J., Macdonald, J., Francis, A. and Smith, A 2017. "A 'Situational Approach' To Mental Health Literacy In Australia". n. pag. Web. 30 May 2017. Accessed via malesuicidepreventionaustralia.com.au/wp-content/uploads/2017/06/Mental_Health_Literacy_Paper_web.pdf

development, career pathways and further qualifications. A building block for lived experience workforce is the Certificate IV in Mental Health Peer Work. This qualification should be seen as the minimum qualification for paid mental health support work by people with lived experience.

There is a need for more investment in lived experience impact in terms of individual roles, specialisations, models of care and system impacts. Research should prioritise impact on improving human rights outcomes, including better approaches to supporting people in crisis and reducing involuntary and restrictive care. The establishment of a national peer workforce organisation is an important step.

Targets for numbers of lived experience roles need to be set across the various mental health workforces. The NGO mental health workforce already employs significant numbers of lived experience workers. Programs like PHaMs require lived experience roles in teams and the decline in funding for this program will reduce the number of jobs. The MHCSA has supported mental health NGOs in SA by developing Standards and Guidelines for NGO employers to help improve the workplace environment[20]. If we lose a high proportion of the current lived experience workforce as appears likely, particularly with Commonwealth mental health programs being defunded, rebuilding will require specific investment in a workforce strategy to ensure high quality pathways to training and employment. The MHCSA is just starting a project to investigate feasibility of a lived experience cooperative to help grow opportunities.

Recommendation 9: Develop and fund a clear strategy to grow the lived experience workforce in both NGO, private and public workforces.

Establish a national peer workforce peak.

Invest in research into the effectiveness of the lived experience workforce in delivering human rights outcomes.

Restrictive practices

The UNCRPD is clear that restrictive practices have no place in modern society. The people we consulted agreed. This includes seclusion, physical and chemical restraint, inpatient and community treatment orders and enforced treatment as well as other more prevalent coercive practices. People told us of being nominally admitted as a voluntary patient but being told that if they tried to leave they would be involuntarily detained.

Recommendation 10: That all states and territories set targets to dramatically reduce all forms of restrictive and involuntary treatment, including physical and chemical restraint, seclusion, involuntary detention and treatment in inpatient settings and the community.

Recommendation 11: That the PC recommend more investment in research to support reductions in all forms of restraint.

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[20] MHCSA 2018. NGO Mental Health Lived Experience Guidelines. Accessed at http://www.mhcsa.org.au/wp-content/uploads/2018/12/LEW-MH-Guidelines_.pdf

Workplace mental health

The issues in workplace mental health are complex and our comment is restricted to the issues raised in our consultation. People told us that there is a need for reasonable adjustment and flexibility so that workers have more options to manage mental illness in the workplace. They also identified that careful and sensitive *performance management is* critical, that workplace policies and practices that support people make a big difference and the need for workplaces to *understand the reality of mental illness when someone is unwell*. supportive adjustments for people are flexible hours, ability to take time off to manage and resolve issues and part-time opportunities. These approaches will also reduce presenteeism. The Mental Health Australia report 'Investing to Save' notes the productivity loss of $60b attributed to mental illness and their key priorities for investment are supported[21].

The growth in the lived experience workforce will also benefit from more flexible workplaces.

> Recommendation 12: That the Productivity Commission consider and make recommendations regarding reasonable adjustments and flexibility in the workplace that better enable people to manage their job and their mental illness.

Welfare and access to super

We were told that mental health carers struggle to meet the definition to receive carer allowance as it is not designed for mental health carers. Easier access to the Disability Support Pension was proposed for people who have significantly reduced capacity to work due to their mental illness and its impacts.

Other issues raised include unreasonable measures such as not providing welfare support for people with too many assets and not allowing people to access super to support periods where they cannot work due to mental illness. An example was given where with a person experienced a period of severe illness but felt extra pressure to keep working or lose the family home.

> Recommendation 13: That the Productivity Commission consider how welfare dollars and superannuation could be used to better help people to support themselves or their family member through periods of illness.

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[21] Mental Health Australia and KPMG 2018. Investing to Save Accessed at
https://mhaustralia.org/sites/default/files/docs/investing_to_save_may_2018_-_kpmg_mental_health_australia.pdf

Summary of recommendations

Recommendation 1:

States and the Commonwealth need to invest at least 50% more in mental health to match the burden of disease.

Recommendation 2:

Use a human rights approach as a lens to assess new investments in mental health, including a strong focus on the 290,000 people with complex support needs.

Recommendation 3:

Review and recommend changes to the relevant Commonwealth states funding agreements to sharpen the human rights focus of state mental health systems including additional KPIs that prioritise recovery. Service innovation funding should prioritise increasing the capacity of psychosocial supports to provide crisis support as an alternative to Emergency Department presentations.

Recommendation 4:

Review Commonwealth States housing agreements and other options to increase access to safe, affordable, secure, stable and appropriate housing for people impacted by mental illness.

Recommendation 5:

The Productivity Commission consider improvements to NDIS for people with psychosocial disability and their families particularly with regard to:

- Plan elements suited to developing and delivering competent psychosocial disability support plans
- Hourly rates for plan elements that ensure appropriate skills, knowledge and experience can be provided by service providers
- Better integration of family carer knowledge and needs into the planning and service delivery process
- Define roles to enhance choice regarding access to qualified lived experience support workers
- Revising entry pathway to reduce the need for people to emphasise the disabling impacts of their illness.

Recommendation 6:

That the PC recommend psychosocial support for the estimated 225 000 people with complex support needs who are not the target of the NDIS. Initially this should be continuation and expansion of existing Commonwealth mental health programs PHaMs, PIR, D2D Living and MHR:Carer Support. Continuous improvement to be based on developing KPIs and data collection focused on human rights outcomes. Key priorities include housing and employment.

Recommendation 7:

That Mental Health Commissions be established in each jurisdiction with a mandate to progress the human rights agenda, with a particular focus on severe mental illness.

That peak bodies for the lived experience voice be resourced in each jurisdiction to bring lived experience and human rights perspectives to mental health reform processes.

That the human rights agenda sit with first ministers in each jurisdiction to reflect the broad collaboration required not just between jurisdiction abut across whole of government.

Mental Health Commissions and lived experience peak bodies to be funded by and report to first ministers in each jurisdiction.

Recommendation 8:

That mental health promotion and literacy investments contain balanced messages that do not inadvertently increase stigma or devalue the important role of the person with illness and their family, friends and community.

Recommendation 9:

Develop and fund a clear strategy to grow the lived experience workforce in both NGO, private and public workforces.

Establish a national peer workforce peak.

Invest in research into the effectiveness of the lived experience workforce in delivering human rights outcomes.

Recommendation 10:

That all states and territories set targets to dramatically reduce all forms of restrictive and involuntary treatment, including physical and chemical restraint, seclusion, involuntary detention and treatment in inpatient settings and the community.

Recommendation 11:

That the PC recommend more investment in research to support reductions in all forms of restraint.

Recommendation 12:

That the Productivity Commission consider and make recommendations regarding reasonable adjustments and flexibility in the workplace that better enable people to manage their job and their mental illness.

Recommendation 13:

That the Productivity Commission consider how welfare dollars and superannuation could be used to better help people to support themselves or their family member through periods of illness.

Appendix one – Survey questions

If you had to explain the 'costs' of living with or caring for someone with mental health issues in both financial and non-financial terms, what would you say they are?

What do you believe helps people with mental health issues to have a sense of meaning and purpose in their lives and allows them to participate in activities and work that is important to them?

Outside of mental health services, what can other service areas - eg education, justice system, housing and social services, etc - do to help people with mental health issues lead meaningful and contributing lives?

What has been your experience with and thoughts about existing ways of understanding mental health issues and how we provide support to people?

What do you think we are currently getting 'wrong' in how mental health issues are understood and supported? How could we improve, or what alternatives would better meet your needs (or those of the person you care and provide support to)?

What do you believe are the biggest barriers to maintaining work whilst experiencing mental health issues or supporting someone who has mental health issues? What could workplaces do to make this better?

If you could suggest *one radical idea* for how to improve things for people with mental health issues what would you suggest?

Do you have anything else you would like to comment on or share related to how mental health issues are experienced, understood or supported and improvements that can be made?

Appendix Two – Key enablers

Key enablers to improve human rights outcomes for people with mental illness were previously identified at a workshop in November 2018. At the consultation forum for this submission, we asked for feedback on these key enablers.

The Key Enablers presented for discussion were:

A movement…

A mental health human rights movement: action by the people will bring about change

Shine a light…

The community should be more aware that human rights are being breached, it should be made not acceptable

Community attitudes need to change…

Community attitude: Community attitudinal change to mental health i.e. it is not okay for practices that result in human rights abuse when responding to a person in mental distress. Change the conversation in community, publicly, in media, in parliament about the need for us to all have mental health literacy.

Prevention: work on mental wellbeing and good mental health rather than a focus on acute mental health beds and being acutely unwell = cultural change

Alternative first response provides a 'social model' option…especially in crisis

Changing the first response and treatment culture of our medical, clinical and mental health sector to adopt and change the culture and environment and make medication last resort as a treatment option.

Support people where they live and not more institutional, involuntary, traumatising care.

Service system applies human rights to design, commissioning etc. e.g. keep people at home in local community instead of institutions and clinical care.

Change culture to reflect human rights values…

Focus on culture and values, not just qualifications, systems and structures e.g. values-based recruitment, values-based leadership, emphasis on human rights not risk adversity and risk management.

Changing culture away from risk management. Advocates easily available for every consumer, advocates as a member of each service. Advocates can provide training in MH and human rights to staff and clients.

Appendix 3. Negative impacts of medications and alternative approaches to clinical treatment such as Open Dialogue and Soteria House

The following information and references was provided by a participant.

Alternative clinical treatment – Open Dialogue and Soteria House

The no. 1 point is we only have a crisis mental health care which is much more costly than having Soteria houses, a place that people can go when they are becoming unwell for respite until they get back on their feet.

A place that has therapy, alternative creative ways to support people in mental distress. Therapists skilled in family therapy and emotional trauma work. Assertiveness courses and empowering therapies.

At the moment people unwind as there is no support, end up in casualty for 2 days as there are no beds, become more paranoid kept in a tiny space, then put on generic heavy drugs, have the shakes and terrible side effects, they can become highly agitated, are not listened to when they have side effects and become more traumatized emotionally as the ward environment is stressful, load brightly lit and they are woken continually to be check on.

The hierarchical autocratic psychiatry dis-empowers takes away their voice and paralyses them.

This environment contributes to them being unwell longer and in hospital which is expensive.

If we have Soteria houses, (a ward at the Repat. could have been perfect families were lobbying for this to no avail) and a democratic open dialogue program that engages the extended family resource, open listening meetings working to create harmony in the home, trust and a democratic process to bring healing to emotional distress, to reach out before things get out of hand we would have empty hospitals as they do in Western Lapland Finland.

That is a huge economic saving!

There program could easily be incorporated into ours, the psychiatrists just need to humble themselves and remember they exist for the patient's best interest not their own ego. ' Everyone's voice is important'

Soteria house references:
https://soteria.org.il/soteria-israel/
https://imhcn.org/bibliography/recent-innovations-and-good-practices/soteria-programme/
https://www.madinamerica.com/2018/02/soteria-israel-a-vision-from-the-past-is-a-blueprint-for-the-future/

OPEN DIALOGUE: an alternative Finnish approach to healing psychosis (COMPLETE FILM)

https://www.youtube.com/watch?v=HDVhZHJagfQ

Negative impacts of medication

Study to support alternative to long term antipsychotic medication.

- Schizophrenia and psychotic disorders are estimated to affect 1% of the population and are one of the highest causes of global disability [1]. They place a considerable burden on individuals, families, and society, with costs amounting to US$62.7 billion in the United States in 2002, for example [2]. The highest costs are related to unemployment, and one long-term follow-up study

found that more than 80% of people diagnosed with schizophrenia have some ongoing social disability [3]

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4524699/

Antipsychotic Maintenance Treatment: Time to Rethink?
Joanna Moncrieff*
Author information Copyright and License information Disclaimer

Summary Points

- Existing studies of long-term antipsychotic treatment for people with schizophrenia and related conditions are too short and have ignored the impact of discontinuation-related adverse effects.
- Recent evidence confirms that antipsychotics have a range of serious adverse effects, including reduction of brain volume.
- The first really long-term follow-up of a randomised trial found that patients with first-episode psychosis who had been allocated to a gradual antipsychotic reduction and discontinuation programme had better functioning at seven-year follow-up than those allocated to maintenance treatment, with no increase in relapse.
- Further studies with long-term follow-up and a range of outcomes should be conducted on alternatives to antipsychotic maintenance treatment for people with recurrent psychotic conditions.

Schizophrenia and psychotic disorders are estimated to affect 1% of the population and are one of the highest causes of global disability [1]. They place a considerable burden on individuals, families, and society, with costs amounting to US$62.7 billion in the United States in 2002, for example [2]. The highest costs are related to unemployment, and one long-term follow-up study found that more than 80% of people diagnosed with schizophrenia have some ongoing social disability [3].

Long-term antipsychotic treatment has been the norm for people diagnosed with schizophrenia and other recurrent psychotic disorders since the introduction of these drugs in the 1960s [4]. Recent data from the United Kingdom indicate that 97.5% of mental health service patients diagnosed with schizophrenia are prescribed at least one antipsychotic [5]. The practice is based on research believed to have established that continuous antipsychotic treatment reduces the risk of relapse. Interpreting the evidence is not straightforward, though, and other data are beginning to emerge that suggest that long-term treatment may have an adverse impact on levels of social functioning [6,7]. Is it time, therefore, to review the practice of antipsychotic maintenance treatment and question whether it should continue to be the default treatment strategy in people diagnosed with schizophrenia or similar psychotic disorders? Go to:

Evidence for Maintenance Therapy

Evidence for the benefits of long-term antipsychotic treatment consists of trials comparing antipsychotic maintenance with antipsychotic discontinuation. In other words, a group of patients already stabilised on antipsychotics are randomly allocated either to continue drug treatment, or to have it withdrawn and, in most cases, replaced by placebo. As a whole, these trials show that patients who have medication withdrawn are more likely to have increased symptoms, usually defined as relapse. However, several commentators have pointed to issues that complicate the interpretation of these "discontinuation" trials [8–10].

Firstly, the fact that antipsychotics, like other drugs, have withdrawal effects has not been adequately acknowledged in trial design or interpretation. Patients allocated to antipsychotic discontinuation are vulnerable to experiencing antipsychotic withdrawal symptoms, which commonly include anxiety and agitation, and which may be mistaken for a relapse of the underlying condition. This possibility is

exacerbated by the fact that there are no agreed-on criteria for relapse. Many studies rely on clinical judgement and others use definitions involving small changes on rating scales scores. These all include non-specific items, such as agitation and hostility, likely to be exaggerated by the physiological changes accompanying antipsychotic withdrawal. Only a minority of studies specify changes in positive psychotic symptoms [11]. Although withdrawal symptoms would be expected to be less prolonged than a genuine relapse, in fact, we know little about their course. It is possible they might persist for long periods following long-term treatment, given evidence on other drugs [12].

Moreover, the experience of antipsychotic withdrawal may, in itself, make a relapse of the underlying condition more likely. The phenomenon of withdrawal-induced relapse has been shown convincingly in relation to lithium in people with bipolar disorder. Patients who stop long-term lithium treatment are more at risk of having a relapse than they were before they started it [13,14]. There is some evidence of a similar effect following antipsychotic withdrawal in people with schizophrenia. Relapses cluster around the point of withdrawal in most studies, for example, and one meta-analysis found that gradual withdrawal reduced the risk of relapse [15], although a recent meta-analysis did not replicate this finding [11]. However, it may be the case that withdrawal over an average of four weeks, as in the included studies in the most recent analysis, is not gradual enough for people who have been on medication for many years. Alternatively, withdrawal-related effects may occur however carefully treatment is withdrawn.

Finally, there is evidence that antipsychotic withdrawal may occasionally be "psychotogenic" in itself, including case reports where withdrawal of antipsychotic-like drugs precipitated psychotic episodes in people with no history of psychiatric disorder [16]. Studies of clozapine show that people can become more severely psychotic after discontinuing clozapine than when they started it [17,18]. The short half-life of clozapine is likely to be relevant to this effect, but some data suggest that a withdrawal-induced psychosis may occasionally occur with other antipsychotics [19].

Therefore, antipsychotic discontinuation studies may partially, or even wholly, reflect the adverse effects of antipsychotic withdrawal, rather than the benefits of initiating maintenance treatment. Further problems with existing studies include the fact that most focus on relapse as their principle outcome, with few providing data on other outcomes such as functioning, quality of life, work performance, or aggressive behaviour and violence. In a recent meta-analysis, for example, only three studies provided data on quality of life. Differences favoured maintenance treatment overall, but the longest study (which was negative) lasted only eight months. Only two studies reported data on employment, with no difference between maintenance and discontinuation groups, and no data on functioning was reported. Five studies reported on aggressive behaviour, which was rare, but more common in people who had antipsychotics discontinued overall. No study lasted longer than a year, however, and most involved abrupt discontinuation [11].

We also know little about how patients balance the risk of relapse against other outcomes. If relapse is not severe, for example, and side effects of drugs are experienced as disabling, patients may accept relapse as a price worth paying. Although some commentators have suggested that relapses worsen outcome [20], evidence from discontinuation trials indicates that symptoms return to normal when drug treatment is re-instated [21,22]. Suggestions that relapse is indicative of a neurotoxic process are also not substantiated by clinical or neurobiological evidence [23–25].

Another limitation of existing studies is that few provide long-term data to match the duration for which most patients are treated. This is a particular concern because of the association of relapse or deterioration with the point of discontinuation. Evidence from the few trials with follow-up lasting over a year suggests that the difference in relapse rates between patients maintained on antipsychotics and those who are discontinued lessens over time [11]. Go to:

Adverse Effects of Long-Term Antipsychotics

Long-term antipsychotic therapy is associated with common and potentially serious complications, so any uncertainty about the benefits of such treatment is a major concern. Tardive dyskinesia, a neurological condition involving involuntary movements associated with cognitive impairment [26], remains common. Recent studies find it affects approximately 4%–5% of people per year who take antipsychotics [27,28]. It is known to be irreversible in some cases and can occur after a few months of treatment [29,30]. Tardive dyskinesia has been recognised for many years, but recent animal and clinical studies have revealed that long-term antipsychotic treatment is associated with reduced brain weight and volume [31,32]. Although we are not certain whether these findings have functional implications, most studies suggest that brain volume reduction is associated with reduced cognitive performance [33].

Antipsychotics are cardio-toxic and associated with sudden cardiac death [34,35]. Some studies report an increased risk of all-cause mortality, even after controlling for other risk factors [35,36], but others report lower risks with long-term treatment [37]. Most antipsychotics cause weight gain of some degree, and some of the "atypical" antipsychotics can cause extreme weight gain, glucose and lipid abnormalities, and diabetes [38,39]. Metabolic abnormalities develop within days of drug initiation [40] and have occasionally been reported to be irreversible [41,42]. Antipsychotics are also reported to be unpleasant to take, causing emotional blunting and sexual dysfunction, among other undesired effects [43,44]. Go to:

New Evidence on Long-Term Treatment

Fifteen- and twenty-year outcomes from a long-term cohort study involving people with early psychosis have recently been published. The data suggest that people who take antipsychotics on a continuous basis have poorer outcomes than people who have periods of not taking antipsychotics [4]. The effect persisted after controlling for early prognostic factors [45]. Moreover, participants diagnosed with schizophrenia, who were not taking antipsychotics, showed better outcomes than those diagnosed with other forms of psychosis (usually associated with a better prognosis), who were on continuous treatment [27]. Nevertheless, confounding by severity is always relevant in a naturalistic study.

The results are supported, however, by data from a seven-year follow-up of an antipsychotic discontinuation study. This study, conducted in the Netherlands with people following resolution of a first episode of psychosis, represents the first really long-term follow-up of a randomised cohort. It consisted of a comparison between maintenance treatment and a flexible and gradual antipsychotic reduction and discontinuation strategy. Only 22% of participants stopped antipsychotics successfully during the randomised treatment period, and 46% never managed to stop them at all. At the 18-month follow up, relapses were more frequent in the group randomised to the discontinuation strategy, in line with other studies [46]. At seven-year follow-up, however, relapses had equalised between the groups, and participants originally randomised to antipsychotic reduction and discontinuation were twice as likely to show a full social recovery as those allocated to the maintenance group (40% versus 18%; p = 0.004) [6]. Symptomatic remission, however, which was achieved by 68% of the original sample, did not differ between the groups (p = 0.78). At follow-up, use of antipsychotics in the antipsychotic reduction and discontinuation group was lower, with 42% using no antipsychotics or very low doses (less than 1 mg of haloperidol equivalent per day) compared to 24% of the maintenance group. A post hoc analysis by treatment received over follow-up, regardless of randomised group, demonstrated antipsychotic discontinuation (or reduction to very low doses) was associated with higher rates of recovery (53% versus 17%; p < 0.001).

The lower neuropsychological functioning demonstrated in participants in the maintenance group at 18 months may indicate the mechanism of the effect on functional recovery detected at seven-year follow-up [47]. Other possible factors, including drug adherence and service engagement, should also be considered, however, although no such data have yet been presented. The Dutch study was conducted in young people who had had only one episode of psychosis. Only 50% of eligible patients agreed to participate. Results may not, therefore, be generalizable to people with longer-term conditions. A recent meta-analysis of antipsychotic maintenance trials found no difference in results between those conducted in people with a first episode and those with recurrent psychotic disorders, however [11]. Go to:

The Future

The majority of people who experience more than one episode of psychosis are currently recommended to remain on long-term antipsychotic treatment, with little guidance about whether the treatment should ever be stopped, and if so, how this should be done. Many patients find this approach unacceptable, and stop of their own accord without support, which likely leads to the complications of sudden medication withdrawal, including relapse.

The studies used to justify current clinical practice do not provide reliable data about the costs and benefits of long-term antipsychotic therapy. In particular, questions remain about how maintenance treatment affects people's overall functioning over the long term, with some indications it may be detrimental for some people. There is abundant evidence that long-term antipsychotic treatment is associated with other serious and disabling adverse effects.

We need to do more research to establish the pros and cons of long-term antipsychotic treatment for people with one or more episodes of psychosis or schizophrenia. Further studies that evaluate a gradual and individualised approach to antipsychotic discontinuation are particularly important, both in people with first episode psychosis, and more challengingly, in people with recurrent conditions. Such studies need to include assessment of outcomes other than relapse and could assess what additional support might facilitate patients to successfully reduce their antipsychotic burden. Longer-term follow-up of five to ten years is required to reflect the duration of treatment in clinical practice. Research on treatments for other medical conditions demonstrates this can be achieved when it is prioritised [48,49].

Response to long-term antipsychotic treatment is likely to be heterogeneous, although so far there has been little success in identifying factors that might predict successful discontinuation [11]. Existing research rarely distinguishes people who recover and are symptom-free between episodes from those who have ongoing positive psychotic symptoms. In the former situation, long-term antipsychotic treatment is aimed solely at preventing relapse, whereas in the latter, long-term treatment may be a form of symptom control, instead of, or in addition to, its desired prophylactic effect. The considerations involved in these situations may be different, and research needs to identify the varying pros and cons of long-term treatment for the two groups. For example, in people who recover completely, the adverse consequences of having reduced social or neuropsychological function may be more significant than for those people who are already somewhat disabled by ongoing symptoms.

While we await the results of further long-term discontinuation studies, I suggest we need to reconsider antipsychotic maintenance treatment as the default strategy for people with recurrent psychotic disorders. In 1976, two leading psychiatrists felt that the cost-benefit ratio of long-term antipsychotic medication was often not favourable for patients and recommended that "every chronic schizophrenic outpatient maintained on antipsychotic medication should have the benefit of an adequate trial without drugs" [50]. Recent evidence suggests that, when risks allow, modern-day clinicians and patients could also consider this option.

Excerpts from the UN Office of the Commissioner for Human Rights - GENEVA (6 June 2017) –

"We need little short of a revolution in mental health care to end decades of neglect, abuse and violence," Mr. Pūras said after presenting his latest report to the UN Human Rights Council in Geneva.

"Mental health is grossly neglected within health systems around the world. Where mental health systems exist, they are segregated from other healthcare and based on outdated practices that violate human rights.

Mental health policies and services are in crisis - not a crisis of chemical imbalances, but of power imbalances. We need bold political commitments, urgent policy responses and immediate remedial action."

Mr. Pūras stressed that psychosocial distress would always be part of the human experience, particularly in the face of growing emergencies, inequalities and discrimination.

https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21689

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Comment: this research paper and Dr Yolande's is enough to engage the Australian government to invest in the programs such as Soteria houses and 'open dialogue' program to avoid a class action from negligence.

Multinational corporations coercive Billion $$ profit driven business has it's hold on research in mental health, withholding damaging evidence in research, influencing those on the DSM panel and damaging children and adults minds irreparably.
Australia must stand against AMA destructive unscientific construction of a mental illness for all human conditions, the significant increase in prescribing for children in recent years is a human rights abuse that will render their lives disabled as is happening.
Psychiatry is a militant organization silencing those dissenters in their own organization.

Evidence of long term damage to the brain, central nervous system which renders a person unable to work or study.

A paper relevant to medication and economic factors.

A Critical Literature Review of the Direct, Adverse Effects of Neuroleptics* *also known as antipsychotics
Dr Kate Dorozenko and Dr Robyn Martin School of Occupational Therapy and Social Work Curtin University
May 2017
https://nmhccf.org.au/sites/default/files/docs/critical-literature-review-antipsychotics-nmhccf.pdf

Human rights violation: the heavy handed standard forced dosing of neuroleptics, and polypharmacy: dominion and forced treatment with outcomes of long term disability due to atrophy of the brain (grey matter shrinkage) tardive dyskinesia, akathisia, Parkinsonism and sudden death, 25 less life expectancy for the consumer.

Chemical torture' is a human rights issue and the Australian government will be sued for allowing pharmaceutical companies to withhold the whole truth in regards to side effects of these drugs and allowing the health system to torture and treat those experiencing psychosis as if a lesser human being. There are alternatives to chemical restraint.
disability by neuroleptics prevents participation in study and work. *

- In stark contrast The 'open dialogue ' program in western Lapland Finland has 70% recovery rates those without ANY neuroleptics, 80% back to work or study within 2 years!!!!!!!!!! We have the opposite statistics following AMA.   SAVING $$$ from drugs and disability.
- Their team has 25 years on the ground experience with a successful program, not in a lab with scientists payed by drug companies but in the real world!!!!! Real life science!!!!

- Sorteria houses have similar recovery and empowering support giving dignity and hope to the person.

I have witnessed:

Tardive dyskinesia is often misdiagnosed as a [mental illness] rather than a [neurological disorder],[11] and as a result patients are prescribed [neuroleptic] drugs, which increase the probability that the patient will develop a severe and disabling case, and shortening the typical survival period.[12]

Other closely related neurological disorders have been recognized as variants of tardive dyskinesia. Tardive [dystonia] is similar to standard [dystonia]but permanent. **Dystonia** is a [neurological] [movement disorder] syndrome in which sustained or repetitive muscle contractions result in twisting and repetitive movements or abnormal fixed postures. Tardive [akathisia] involves painful feelings of inner tension and anxiety and a compulsive drive to move the body. In some extreme cases, afflicted individuals experience so much internal torture that they lose their ability to sit still. Tardive [tourettism] is a [tic] disorder featuring the same symptoms as [Tourette syndrome]. The two disorders are extremely close in nature and often can only be differentiated by the details of their respective onsets. Tardive [myoclonus], a rare disorder, presents as brief jerks of muscles in the face, neck, trunk, and extremities.[9]

Akathisia: Around half of people on antipsychotics develop the condition.[6

Symptoms of akathisia may vary from a mild sense of disquiet or [anxiety] to a sense of terror.[8] People typically pace for hours because the pressure on the knees reduces the discomfort somewhat; once their knees and legs become fatigued and they are unable to continue pacing, they sit or lie down, although this does not relieve the akathisia. When misdiagnosis occurs in antipsychotic neuroleptic-induced akathisia, more antipsychotic may be prescribed, potentially worsening the symptoms.[9] Neuro-psychologist Dennis Staker had drug-induced akathisia for two days. His description of his experience was this: "It was the worst feeling I have ever had in my entire life. I wouldn't wish it on my worst enemy."