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ROYAL COMMISSION INTO VICTORIA'S MENTAL HEALTH SYSTEM

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1. In the course of this submission about the importance of human rights to the reform of Victoria's mental health system, I will take the opportunity to speak of the experience of my wife, Tricia Byrnes, and I with our late daughter, Jessica.
2. Jessica was born in 1980 and died of a drug overdose in 2003. She was the eldest of three children, the others being a brother born in 1983 and a sister born in 1989. She was a bright and happy child who grew up in a loving family. At about 13 years of age, she became mentally unstable and was eventually diagnosed with bipolar disorder. She endured hell with that illness for the next decade.
3. Respecting the dignity of every person and ensuring equality and non-discrimination must be the starting point for any discussion about the mental health system. Jessica was a normal teenage girl from a young family. While mental illness is more prevalent among some vulnerable groups, it can and does strike anybody, as her experience demonstrates. She was nothing more nor less than a person who loved and was loved, who gave and received and who had the potential to develop and flourish like everyone else. Every person who has or might develop mental illness, like Jessica, is entitled to respect, equality and non-discrimination as a matter of fundamental human rights. When, like her, the person is a girl and later a woman, an age and gendered perspective is required. Prejudice and stigma must occupy neither hidden places in our minds nor public places in our discourse when considering the adequacy of the mental health system.
4. The circumstances in which Jessica was first admitted to a psychiatric hospital were that, sometime after her behaviour began to deteriorate, she started to 'hear' threatening voices and 'see' threatening people. She had already experienced several manic episodes, which the family did not understand or know how to handle. We understood that hearing threatening voices and seeing threatening people was indicative of mental illness, so my wife and I called the CAT Team. A mixed-gender team arrived, and they treated Jessica well. They said she was 'psychotic' and 'paranoid', and she went with them to a psychiatric hospital. After being assessed by a female psychiatrist, she was placed on an order, which she unsuccessfully appealed, and was coercively medicated.
5. Human rights are not just about negative freedoms; they are also about positive entitlements. The right to health is central to human existence and flourishing. A mental health system was there to help Jessica when she needed treatment for her mental illness, although it was not targeted specifically to the needs of young people generally or young females in particular. Her order was subject to independent oversight, which she could and did access personally. This is a universe away from the asylum era. But it was and is a one-size-fits-all system, one that is built upon a blunt medical model, one that does not generally apply an age and gender perspective and one in which coercion is a central and not a back-up component: admission, diagnosis, compulsory order, compulsory medication, stabilisation, discharge, medical supervision in the community (not care-support), rewind, play again. It is a very familiar path that is too often associated with chronic mental illness, as it was with Jessica. Also, unfortunately, her needs as a girl in her teenage years were not a feature of the treatment.

6. There was no such thing as early intervention in those days. We did not know where to turn and did the best we could with the system as it was. We were grateful for it. If there was a Headspace available, we and (I believe) Jessica would have used it. We were actually a well-functioning family and she was an engaging and intelligent teenage girl. In terms of adopting a broad care-support model (encompassing medical treatment when necessary) instead of a narrow medical-treatment model, her case presented significant possibilities. Back then, as it mostly is now, the thinking was binary: sick/not sick; order/no order; medication/no medication; risk/no risk; admission/discharge. This set the pattern for the next decade during which events deteriorated so seriously and quickly that we always felt, and actually were, completely out of our depth.
7. It is now abundantly clear that this kind of false binary thinking is the enemy of a mental health system that respects dignity and human rights. It is too often based upon an essentialised and discriminatory notion of who a person with mental illness is and what they need: once the person is diagnosed with mental illness, that is how they are seen, and they receive the treatment that people like them receive in the system. In my personal, professional and judicial experience, people with mental illness present with various (and sometimes fluctuating) levels of illness and symptoms, susceptibility to treatment, capability strengths and weaknesses, social and family supports etc. They are as diverse as the richness of humanity itself, to which they contribute, as Jessica did. In human rights terms, their personal characteristics and social determinants of health do not come in locked-up boxes marked 'mentally ill, no need to open'. People may be living with mental illness quite well, despite all outward appearances. In an ideal system, Jessica's case could be approached by identifying where across a wide spectrum her personal situation should be plotted, taking gender and age into account. Depending upon that assessment, particular care-support options (including medication if necessary) could be chosen, targeted to her as a teenage girl and then a young woman. As a matter of system design, that is not how things worked then and it is not how things work now.
8. Unfortunately, Jessica's condition became worse. Her behaviour was impossible for the family to manage and she went into state care. She visited and stayed with the family often, but never returned full-time. Drug abuse entered and ultimately ended her life. She lived mainly in the community, was usually unwell, but functioned as best as she could with our help. She formed a loving relationship with a kind, supportive young man who also lived with mental illness. The couple were allocated social housing until they moved closer to us in private rental accommodation that we supported. During the last of her several admissions, she absconded, took an overdose of drugs (following a period of abstinence) and died, intentionally or unintentionally we do not know.
9. When Jessica died, she was at least 120kg in weight. She was only about 163cm in height. As a former president of the Forensic Leave Panel, I am now aware of the enormous treatment value of certain medications but also their potential impact upon a person's weight and appearance and therefore their body image and self-esteem. During Jessica's decline, I was not. I did raise concerns about her weight with doctors but was persuaded that nothing could be done. Jessica was very distraught about her

weight and appearance. I felt and still feel a real sense of failure about not being able to get on top of this issue. If I had my time again, I would take the issue of medication and side-effects a lot more seriously.

10. Some may think that this is a trivial issue in the context of mental illness. I can use human rights principles to explain why it is not. The critical consideration is respect for autonomy and agency. A correlative consideration is respect for the role of the family and other social supports. These considerations come together around the important obligation of government to ensure the provision of adequate health information, which is part of the right to health. From the outset, Jessica was never provided with much information about the medication she was prescribed or its side-effects. She was probably given basic information. But nothing was given to her (or us) that allowed preparation for the change in her appearance and behaviour (drowsiness and slurred speech) that was to come. To this day, I am unsure of the details of the medication. I am much better equipped now to look into this issue, but back then I was just a father who was not well-informed.
11. This demonstrates how powerless a person with mental illness can be in the clinical setting. The power is held by the clinician, usually a doctor, who is expected to know all and cure the patient in the patient's best interests. The patient has the right to refuse treatment but may be coerced if they do so. The doctor offers the hope of amelioration or cure (or recovery), and side-effects can seem a side-issue in the whole context. In fact, they can become part of the problem, as they did in Jessica's case. The provision of information sufficient for the exercise of informed consent is fundamentally important in this situation, for the patient and their social supports. Human rights reflect this fundamental importance.
12. Human rights are indivisible, interdependent and interrelated. Within the unitary system of human rights, the two that figure here are:
 - The right to health
 - The right to personal autonomy and agency
13. The right to health is not a right to be healthy; it is a right to the highest attainable standard of physical and mental health. It includes the right to obtain adequate information about the condition and treatment.
14. The right to personal autonomy and agency is itself wrapped up in the right to health for the exercise of self-determination is integral to health and wellbeing generally. The two kinds of rights exist in an indivisible, interdependent and interrelated relation. There is no zero-sum trade off. People and life and the experience of mental illhealth are not that simple. The exercise of autonomy and agency is especially important for people with mental illness. They fear the loss of it due to both the illness and the treatment, or a combination of both. This contributes to their sense of powerlessness and makes them especially vulnerable to decisional domination.
15. Every doctor, clinician or allied professional who assisted Jessica and our family was caring and devoted to making her well (this was too early for the recovery model of care to have much influence). That they did not succeed was not their fault or our family's fault. All did their best within the system as it was then designed. My family is

immensely grateful for the treatment and support of literally dozens of people over the decade of Jessica's decline.

16. But I am left with a strong sense of failure and regret that especially forms in my mind when I recall a conversation that I had with Jessica when she was about 21 years of age. Her partner and I were talking with her about her mental illness when she looked into my eyes in complete calm but in a pleading way and said: 'it [the illness] is robbing me of my potential'. This is a sad but treasured memory for a father to have of his late daughter. Much more than that, Jessica was a person who inspired people and this remark inspires me to remake, with emphasis, the point that equality, non-discrimination and respect for dignity are fundamental to the issues before the Royal Commission. Despite all the suffering that Jessica endured, she saw herself to be a person with potential. I have seen that sense of self-potential in virtually all of the hundreds of patients at the Forensic Leave Panel for which I later became responsible. It is our responsibility to give effect to their human right to achieve that potential to the maximum extent that is possible, remembering that age and gender discrimination are prevalent in all parts of society.
17. I think it is very clear that Victoria's mental health system is not ensuring equality, non-discrimination and respect for dignity. In my view, four prominent problem areas are:
 - Poor system design
 - Inadequate resources
 - The missing middle
 - Dominant paradigm: best-interests paternalism
18. My personal and professional experience is that Victoria's system, like those of many in the developed world, is founded upon a singular conception of mental illness as a disease rather than upon a nuanced conception of mental illness as both a disease and a condition that gives rise to disability in the social context. It is as if the great moral and normative breakthrough that occurred with the *Convention on the Right of Persons with Disabilities* (2006) has not been internalised and operationalised. The consequence is a disproportionate emphasis upon medical treatment often coercive rather than upon a spectrum of care-supports that include that treatment. The system is not very innovative, with some highly significant exceptions (eg Orygen and Headspace, and Beyond Blue). Consumer involvement in the system is miniscule; the insights of those with lived experience of mental illness are neither highly valued nor structurally incorporated into the system; and there is a wide and unhelpful clinical/consumer divide. Research into different models of care is generally lacking and not seen to be urgently required, which it plainly is. A new and sophisticated model of care-support that respects the human rights of people living with mental illness should be seen in the same light as a life-saving vaccine. University education of medical and like professionals, especially doctors, is narrow. The clinical professions and teaching academies do not appear to be leading change (again, there are some significant exceptions). There is an impoverished understanding of human rights within the system, in which those rights are but weakly operationalised, despite the Victorian Charter.

- Human rights concepts are not actively employed to describe the essential features of the system and its deficiencies despite their obvious pertinence and explanatory power.
19. I would favour a system in which these parameters were basically reversed without losing the capacity to provide medical-based treatment (within a broad care-support model) when necessary. Because mental illness and recovery (in the well-understood broad sense) are a function of social determinants as well as biology, a public health approach would play an important role in such a system. Indeed, only a public health approach, with other population-wide measures, can effectively address the social determinants of mental health. However, the system must be underpinned by the normative foundation of human rights to ensure equality, non-discrimination and respect for dignity. A public health strategy is an organised program of action which should be underpinned by but cannot substitute for human rights as that normative foundation. Moreover, human rights themselves are a determinant of mental health.
 20. When binary thinking dominates the mental health discourse, it is natural to ask whether non-consensual medical treatment is contrary to human rights *per se*. A dominant medical treatment/no medical treatment paradigm is apt to generate a consensual treatment/non-consensual treatment choice. What can one expect when that is the professional model that is drilled into our medical professionals (see further below)? This gives rise to serious equality, discrimination and dignitarian criticism of the kind made of the Victorian system, to which abolishing non-consensual treatment altogether seems to be a ready answer.
 21. Those who speak in favour of some place for non-consensual treatment in a (arguably) human rights compliant system address themselves to a narrow class of case in the residual category. They do so on right to health grounds. They do not see the medical model to be outmoded and irrelevant, as some would argue. They call it in aid in that residual category that may exist even after ideal reforms have been implemented and the system is shaped very differently to the one that we have now.
 22. By contrast, a system that is characterised generally by the use of non-consensual treatment (compulsory order/no compulsory order) as a way to allocate publicly funded treatment has forfeited its claim to human rights legitimacy because it is based on expedience, not proportionality. On the evidence before the Royal Commission, Victoria's mental health system appears to have reached that point.
 23. When considering how to reform a system having this fundamental deficiency, it is prudent to turn to the empirical research available. People with mental illness are not crash-dummies. A primary criterion for a health reform to meet is the 'do no harm' principle. Although the early signs in the limited research available are apparently promising, I am not aware of any which establishes that, without some degree of non-consensual treatment, however residual, the system will not leave certain people with mental illness to an untenable fate.
 24. Resolution of this issue must not become an obstacle to fundamental reform in the direction of equality, non-discrimination and respect for dignity. There is so much to do, so much that can be done and so much that must be done. It is categorically imperative. It would be fundamental reform to redesign the system along care-support lines where

medical treatment was one option among many; where government funding was significantly scaled-up; where clinical innovation was encouraged; where our brilliant and best clinical scholars saw this as a lighthouse issue; where an age and gender perspective was adopted; where the system was supported by a significant public health effort; where the consumer voice was stronger and more valued; where tertiary education and training included not just professional ethics but fundamental human rights; where substituted decision-making was (at least all but) abolished in favour of supported decision-making that was properly informed by the person's will, preferences and rights; and where the system was underpinned by the human rights normative framework in practice and not just in legalisation. If reform of that kind is possible, it should not be held up by resolution of the bigger question. There are significant international and domestic voices speaking for resolution of that question in favour of abolishing non-consensual medical treatment. In my view, this objective should be kept firmly in view and may ultimately be achieved or near-achieved, but reform of the kind that I have described is simply too urgent to wait.

25. Turning to inadequacy of resources, I support the evidence before the Royal Commission that Victoria's mental health system is chronically underfunded. Without a substantial increase in public investment, the problems in the system cannot be addressed. In human rights terms, this is a matter of obligation, not policy. Victoria is not like a developing nation where lack of resources is an explanation for under-investment in health.
26. Victoria finds itself in the position of having a Royal Commission into the mental health system only six years after the 2014 reforms to the legislation. That legislative investment should have returned a better yield than it did. Although the 2014 legislation now seems obviously in need of modernisation in the direction of human rights, this is not surprising in a dynamic field like mental health reform. Back then, the legislative changes were very positive. But they were helicoptered into a system that was organised along legacy lines and did not receive operational reform and upscaled funding to match the legislative expectations. The message to be learnt is that you can have legislative reform, you can have operational reform (including major cultural change: see below) and you can have upscaled funding. However, to have system reform you need to have all three of these together, underpinned by a fit-for-purpose normative foundation.
27. The 'missing middle' is an expression that has gained traction as a way of describing a gap in the system in the area of non-acute care. A person can be mentally well without needing care or very unwell and receive (often coercive) care. But if the person's health is in the middle, the person may find it difficult to find the middle kind of care. I support the thinking behind the submissions on this subject. They align with my personal experience with Jessica. We were very familiar with the admission-discharge-community monitoring cycle. In that cycle, community monitoring is supposedly the means by which non-acute care is given. In our experience, it is actually the means by which the person's medication and condition are monitored. Community-based care as we experienced it was strongly influenced by risk management considerations. As

parents we did not feel that Jessica was being treated within a system of community-based care-support. I am not suggesting that she did not receive medical treatment in that setting, rather that the treatment purpose was narrow and certainly not holistic, and of course it was impossibly under-funded. I applaud the steps being taken by some innovative providers to address this problem in the field and by some tertiary institutions to research and develop innovative ways of doing so.

28. I will end this submission with some remarks about the dominant treatment paradigm in Victoria's mental health system best interests paternalism. This paradigm is contrary to human rights and contemporary thinking about the relationship between clinician and patient in a recovery-based therapeutic setting. I expected the 2014 legislative reforms to do more to shift this paradigm than they did. For this objective to be achieved, it is now clear that major cultural change is needed.
29. Upscaled funding is a fundamental part of the solution. When highly-stressed psychiatrists and others are compelled to work in a state of constant crisis, is it any wonder that they fall back on a binary care model? It is only natural to think in terms of heuristics (general rules) that the system endorses when there is simply insufficient time or inadequate resources for the higher kind of reasoning that human rights requires. That mainstream medical-model reasoning about this subject is so black and white is a reflection of the system as it is and offers no insight about the capacity for clinicians not just to change but to lead change in an scaled-up system as it could be.
30. But it is not a sufficient solution. As I stated above, reform in (at least) three areas is necessary: legislative, operational and financial. The problems in the system cannot be addressed simply by throwing more money at it. An important problem area is the dominant culture of best-interests paternalism. While the post-2014 reform experience shows that this culture is difficult to shift in an under-funded system, it does not follow that it will shift of itself if funding is upscaled. I do not think that anyone wants to see an outcome in which that problem is bigger because the (upscaled) system is bigger. We need an upscaled system that is not just bigger, but different and much better.
31. Of the many insights into people with mental illness that Jessica left me is the insight that there is a subjective and an objective dimension to the experience of mental illness. Every person with mental illness is different, but they all share the experience of that illness. Because this ontology (state of being) is different to that of people not living with mental illness, it is not easy for each fully to understand the other. Complete understanding is actually not necessary, although it must be maximised. Complete respect is absolutely necessary, and it must never be minimised. The organisation of the present system is not fully conducive to ensuring that this understanding is maximised and that respect is never minimised. I do not think this can happen when the voice of people with mental illness is muted by the system, when their experience is not sufficiently valued and when they are not included in system design, delivery and innovation when appropriate. Participation by vulnerable groups in system design and support is a fundamental human rights principle. This is not just rights-speak. It operates to improve system and care outcomes.

32. My experience in this and related fields is that cultural change has to be led from the top (the apex political leadership) and permeate the system as a whole. All participants in the system need to know what is expected of them. Legislation, good governance, the judiciary and tribunals, industrial relations, human resource management, occupational education and training and tertiary education and research must all play a part. Respect for human rights at the level of deep culture within the system is indispensable. We are dealing with a highly vulnerable group of people. Whatever else is done, only the normative framework of human rights can ensure that the system operates in accordance with the fundamental principles of equality, non-discrimination and respect for dignity.

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