

Trajectory: Changing the Direction

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Health and Human Rights both provide leverage that can be applied to improving the life trajectory for the most vulnerable citizens. At a population based level, health can advocate for the provision of accessible services and act as ethical guardians. Human Rights advocacy provides a view that takes in the bigger picture that lies outside the influence of health. Both perspectives need to be harnessed to ensure the quality of life for those with an intellectual disability and mental illness. *"The recognition of human rights as a determinant of health opens up avenues for intervention in the pursuit of improved public health that may not have been realized in the past"* (Exploring synergies between human rights and public health ethics: A whole greater than the sum of its parts. Stephanie Nixon^{12*} and Lisa Forman³. BMC International Health and Human Rights 2008, 8:2 doi:10.1186/1472-698X-8-2)

All the papers listed below examine and report from different angles on the status of Australia's response to those with an intellectual disability and mental health conditions and the potential for a more unified approach.

Like the Russian Matryoshka nesting dolls, these papers sit within one another, each an outcome within another place along a trajectory. All illustrate the critical need for sectors to work together on both the Human Rights and health fronts to improve the quality of life for those children and young people identified as being in this vulnerable section of the population. The final paper provides a picture of how the strengths of each can effectively reinforce the work of the other.

UN – Convention on the Rights of Persons with Disabilities: *concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 Sept 2013)*

The perspective provided by the UN report captures both the positive steps and areas of concern for Australia. It acknowledges and commends the adoption of the National Disability Strategy 2010 – 2020 as a mechanism for implementation of the Convention across jurisdictions. It notes with approval the introduction of the national disability insurance and the Australian Law Reform Commission inquiry into matters of equal recognition before the law.

The report notes the Committee's concerns around the degree of participation by those with disabilities and their representatives in the development of policy and legislation and the level of resourcing available to organisations that provide advocacy and support. It also recommends that the State strengthen the Disability Discrimination Act 1992 to more clearly cover the all those with a disability including

children, woman and children, indigenous, hearing impaired, deaf and those with psychosocial disabilities.

Left Behind- Monitoring the social inclusion of young Australians with self-reported long term health conditions, impairments or disabilities: 2001- 2009. Professor Gwynnyth Llewallyn, Professor Eric Emerson, Dr Anne Honey, Dr Maina Kariuka – Faculty of Sciences University of Sydney.

This report gathered and compared measures of social inclusion of those aged between 15 – 29 with and without disabilities over the years 2001- 2009. This showed significant differences. Disabled young people were less likely to be employed, engaged in education and more likely to be living in a jobless household, have low economic resources and experience financial stress/material hardship. They were also more likely to have mental health illness and poor overall health. Over the nine year time period young disabled people in Australia were up to five times more likely to have experienced multiple disadvantage and entrenched disadvantage. The report highlights the widening gap between the living conditions of disabled and their non-disabled peers. Although not specifically measured within the bigger picture presented in this report, the gap is sure to be even wider and the life trajectory for those with an intellectual disability and a mental health illness a much tougher one.

Intellectual Disability and Mental Illness: *The RANZCP paper Oct 2012*

The Royal Australian and New Zealand College of Psychiatrists take this further in the October 2012 position paper, Intellectual Disability and Mental Illness. It focuses attention on the relatively high prevalence of mental ill health (psychiatric and neurobehavioural disorders) in the population of those with an identified intellectual disability. This difference across all ages is 30 – 40%, a threefold increase in prevalence over the general population. They also add that there is further 1% with unidentified ID with even higher levels of mental health problems.

The RANZCP paper draws attention to particular sub-section of populations such as young people with autism. A proportion of them will have intellectual disability with clinically significant levels of psychopathology at times.

The high rates of mental ill health, poor general health and shorter life expectancy of those with an intellectual disability have been documented in the National Health and Hospitals Reform Commission report in 2009.

The paper includes reference to the many reports and studies that have consistently noted the lack of services and



training psychiatrists, mental health and general practice in assessing and meeting the needs of those with intellectual and developmental disorders. This is described as a form of systemic discrimination. To quote the RANZCP; "The lack of specialist services, barriers to accessing mainstream services and the lack of specific expertise results in poor standards of care and poor outcomes, such as individual suffering, indiscriminate chemical restraint, poor health outcomes, increased carer burden and costs to the community". In 2010 the RANZCP set up a Special Interest Group in Intellectual and Developmental Disabilities to promote the study, research to advance understanding and improve the lives of those with intellectual/developmental disabilities and mental health problems. A focus of this group has been on advocating for specific training for health professionals and recommendations on health policy that advance the mental health needs of those with intellectual/developmental disabilities a priority.

The Involuntary Detention of People with Intellectual Disabilities – Human Rights in Australia: Human Rights in Australia Oct 30th 2012. Author: Bernadette Mc Sherry, Professor of Law and Director of the Centre for the Advancement of Law and Mental Health, Monash University.

A related publication is an article by Professor Bernadette McSherry in Human Rights in Australia. The Involuntary Detention of People with Intellectual Disabilities (published Oct 30th 2012) examines the laws in relation to detaining those with an intellectual disability in Australia. While all states have guardianship laws that enable decision making where the individual is considered unable to make their own decisions some states have other laws that mean a person with an intellectual disability can be held in a certain facility without their consent for indefinite periods of time. Section 32 of the Guardianship and Administration Act 1993 gives the Guardianship Board the power to order a person under guardianship to be detained in a specific place. This power is underlined in the statement that the Guardianship Board may 'authorises the persons from time to time involved in the care of the protected person to use such force as may be reasonably necessary for the purposes of ensuring the proper medical or dental treatment, day to day care and wellbeing of the person'.

In both Victoria and Queensland there is legislation that enables the indefinite detention of individuals with an intel-

lectual disability who have been charged with or convicted of an offence punishable by imprisonment. (As a New Zealander I must acknowledge there is a similar piece of legislation there called the Intellectual Disability Compulsory Care and Rehabilitation Act)

Professor McSherry highlights in the article the human rights gap in state laws where a person may be placed in indefinite detention in a secure facility having been found 'unfit to plea' because of intellectual disability. She notes that at the time of publication (Oct 30th 2012) work had begun on a High Court challenge to the constitutional status of laws that allowed those with an intellectual disability, who have been found unfit to plea, to be held in prison indefinitely. She notes that Indigenous Australians with intellectual disabilities are over represented in this context. The variations across Australian States around this aspect of the law is an important issue in itself as presents a potential national abrogation of duty in terms of human rights.

People with mental health disorders and cognitive impairment in the criminal justice system: Cost-benefit analysis of early support and diversion. UNSW & PWC.

A perspective on the realities and systemic cost of this position is evident in a cost-benefit analysis of early support and diversion in a study done by UNSW and PwC. Titled 'People with mental health disorders and cognitive impairment in the criminal justice system' it outlines, using case examples, the human and financial benefits of effective early assessment, support and cross sectorial/ disciplinary work.

Opening with statistics of the known prevalence of mental health conditions, psychotic disorders, intellectual disability and brain injury in both the general population in NSW and those in the criminal justice system, the differences are starkly apparent. Young people with mental health disorders and/or cognitive impairment are at least 6 times more likely to be in prison than their non-disabled peer group in the general NSW population. For Aboriginal young people, the potential for becoming a client of Juvenile Justice is 13.2% compared with 1.4% for non-Aboriginal.

The Justice system provides one of the few areas where relative costs can be calculated. Unlike other aspects of social intervention, legal consequences can be accurately counted. The cost of juvenile justice services, institutional stays and custodial time and engagement with health professionals can all be quantified with some accuracy. The case examples illustrate how the potential for intensive early intervention could have affected both the individual personal outcomes and the longer term costs. The trajectory traced by the case examples illustrate how earlier intervention had potential to make a huge difference. In a case study of a 20yr old, in the total combined cost of Police, Juvenile Justice, health and other agency involvement was calculated as \$5,515,293. These costs are shown to have fallen considerably with engagement at age 18yrs with NSW ADHC Community Justice Programme.

The study's authors propose this shows that if the young person's intellectual disability and personality disorders

had been identified as a key factor much earlier, it may have modified the history of involvement with the justice system, self-harm, physical abuse and trauma and the onset of other mental health illness.

The paper reinforces the need for policy makers to regard early intervention services for those with intellectual disability and mental health illnesses as an investment in future outcomes rather than a cost burden on the State.

“At the inter-sectorial level government departments need to continue building and implementing collaborative practice...”

Exploring synergies between human rights and public health ethics: A whole greater than the sum of its parts. Stephanie Nixon

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BMC International Health and Human Rights 2008, 8:2
doi:10.1186/1472-698X-8-2

This paper argues that the interests of human rights and public health intersect and have a synergy that benefits both. “The balance of this paper articulates how an approach that combines human rights and public health ethics can make a comprehensive contribution to the normative analysis of health issues than either approach made alone”.

It sets the growing disparities in health and wealth within nations and internationally as a challenge for both fields. It quotes Jonathan Mann’s call for a collective approach to emerging health issues that encompasses medicine, public health ethics and human rights as a starting point for this paper. “Mann’s thesis about the interconnectedness of health and human rights contributes to the understanding of what makes people healthy or ill [47]. This recognition that the protection of human rights is itself an important determinant of health is largely absent from the discourse on determinants”.

The authors are very clear on the human rights obligations of states toward their citizens as a critical fulcrum. “At a time when many developed country governments are reducing public expenditures on health, and after decades of structural adjustment programmes that have forced the same neoliberal reasoning on developing countries, a refocus on states’ legal obligations to progressively realize the right to health of all citizens offers added ammunition in both advocating for public health and, where necessary, litigating for specific health care services”.

They note the current debates over what constitutes healthy public policy and the role of the private sector in delivering health care and the human rights doctrine that places responsibility for health with governments rather than the view “:that health is a commodity that ought to be regulated by the market”.

Although it does not specifically discuss disability, the focus in the paper on the issues around the right to health and public health ethics is very relevant to the particular concerns of those who work with mental health within the intellectually disabled child/adolescent population in Australia and internationally.

The author’s sets out how public health ethics contributes to human rights by reinforcing the normative claims in international human rights law, which strengthen advocacy and the links between public health and human rights. In the other direction the contribution of human rights comes from defining the right to health and the indivisibility of rights alongside the duty of states to respond to the health needs of population and the acknowledgement and inclusion of human rights as a determinant of health.

This last point is particularly relevant in countries where indigenous peoples and other vulnerable population groups health needs are being considered. The paper discusses the human rights lens as an effective viewpoint in addressing the health concerns of marginalized individuals and populations, with a reminder of the 10-90 gap. This refers to the 10% of global health research resources spent on 90% of the world’s health issues. The influence of human rights is seen as crucial to encouraging public health to act on the ‘chronic neglect of issues facing the world’s most vulnerable populations.

Health as a ‘free-standing’ human right has been incorporated into various international treaties and regional human rights systems and these rights have become more than simply advocacy rhetoric but actual enforceable legal rights. In their summary the authors see the ‘soft’ contribution of ethics as contributing and complementary to the ‘hard’ legal frameworks of human rights with both reinforcing what they describe as the untapped potential for collaboration between public health and human rights and the contribution rights and ethical standards can make to achieving more equitable outcomes across populations.

Summary: All the above papers consider an aspect of the life trajectory for those with an intellectual disability and mental health problems. The issue of policy design across the ministries of welfare, justice, health and education is evident in all of them. Within the big national perspective there is a duty that comes with signing international protocols and building nationwide law reform that reinforces the rights of those with disabilities. At the inter-sectorial level government departments need to continue building and implementing collaborative practice. The communities of Australia need continued encouragement to support those with intellectual disability towards equal access to health services and social inclusion.