‘DYING TO BE COUNTED’: THE SOCIAL DETERMINANTS OF HEALTH AND LGBTI AUSTRALIANS

SUBMISSION TO THE SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS INQUIRY: AUSTRALIA'S DOMESTIC RESPONSE TO THE WORLD HEALTH ORGANIZATION'S (WHO) COMMISSION ON SOCIAL DETERMINANTS OF HEALTH REPORT "CLOSING THE GAP WITHIN A GENERATION"

ABOUT THE GAY & LESBIAN RIGHTS LOBBY

Established in 1988, the NSW Gay & Lesbian Rights Lobby (GLRL) is the leading organisation for lesbian and gay rights in NSW. Our mission is to achieve legal equality and social justice for lesbians, gay men and their families. The GLRL has a strong history in legislative reform.

In NSW, we led the process for the recognition of same-sex de facto relationships, which resulted in the passage of the *Property (Relationships) Legislation Amendment Act 1999* (NSW) and subsequent amendments. The GLRL was also successful in campaigning for an equal age of consent in NSW for gay men in 2003 and the equal recognition of same-sex partners in federal law in 2008.

The rights and recognition of children raised by lesbians and gay men have also been a strong focus in our work for over ten years. In 2002, we launched *Meet the Parents*, a review of social research on same-sex families. From 2001 to 2003, we conducted a comprehensive consultation with lesbian and gay parents that led to the reform recommendations outlined in our 2003 report, *And Then … The Bride Changed Nappies*. The major recommendations from our report were endorsed by the NSW Law Reform Commission's report, *Relationships* (No. 113), and enacted into law under the *Miscellaneous Acts Amendment (Same Sex Relationships) Act 2008* (NSW). In 2010, we successfully lobbied for amendments to remove discrimination against same-sex couples in the *Adoption Act 2000* (NSW).

INTRODUCTION

The NSW Gay and Lesbian Rights Lobby welcomes the opportunity to provide comment on this inquiry into Australia's domestic response to the report of the World Health Organisation's (WHO) Commission on the Social Determinants of Health (CSDH), titled 'Closing the Gap Within a Generation' (hereafter referred to as the WHO CSDH report). The NSW GLRL is mindful of the historic background to the WHO CSDH report, reflecting years of consultation, as well as the ongoing engagement of the WHO on this issue, including through the recent World Conference on the Social Determinants of Health, held in Rio de Janeiro in October 2011.

In this brief submission, we intend to focus on two of the terms of reference for the inquiry, providing detailed commentary in our area(s) of expertise. These terms of reference are: (C), the "extent to which the Commonwealth is adopting a social determinants of health approach" and (D), "scope for improving awareness of social determinants of health". Our comments are primarily directed at government agencies, in relation to routine data-collection practices in the health and social service sectors and also community organisations and public sector agencies in relation to the scope for improving awareness of the social determinants of health, including sexual orientation and gender identity.

From the outset, it is particularly important to note that sexual orientation, or gender identity in, and of, themselves, are not causally related to poor health outcomes, but are rather the basis for differential treatment, and in many cases, discrimination, rendering them social determinants of health.

(C) EXTENT TO WHICH THE COMMONWEALTH IS ADOPTING A SOCIAL DETERMINANTS OF HEALTH APPROACH

(iii) Appropriate Commonwealth data gathering and analysis

The routine collection, regular disaggregation and frequent reporting of health and wellbeing data, as well as data on the social determinants of health, is critical to the realisation of one of the cornerstones of modern democracy - the right to be counted. In this respect, the WHO CSDH report advocated for the adoption of "national and global health equity surveillance systems with routine collection of data on social determinants and health inequities[1]". This signals the centrality of robust and reliable data collection concerning the social determinants of health, which are now widely recognised as including sexual orientation and gender identity[2,3], to the realisation of this right.

In Australia, the collection of reliable demographic data for LGBTI people, essential for the establishment of such a surveillance system, is variable across Commonwealth agencies and departments, and in some cases non-existent, with different data-sets containing distinct data-fields for identification[4]. This has knock-on effects for measuring socio-economic outcomes, for instance, which are central to most efforts to monitor and report on the interaction between various social determinants of health (such as socio-economic status and sexual orientation, for instance). The paucity of available information in areas such as socio-economic data as well as mortality data[5], effectively hinders the ability of LGBTI community organisations and researchers to ensure accountability for health outcomes. This primarily occurs through impeding our ability to answer the central question of accountability in health: "who and what drives current and changing patterns of social inequalities in health?[6]" We do, however, note and applaud the efforts of an increasing number of Australian researchers to systematically collect and analyse data relevant to the health and wellbeing of LGBTI Australians[7].

The NSW GLRL notes that, as with many other population groups who have been historically marginalised, the lack of data collection in spite of demonstrable 'need' on the ground, results in a

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[1] Commission on the Social Determinants of Health (2008). *Closing the Gap within a Generation*. Geneva: World Health Organization, p. 21.

[2] World Health Organization, (2006). *Defining sexual health: report of a technical consultation on sexual health, 28–31 January 2002, Geneva*. World Health Organization: Geneva.

[3] Logie, C. (2011). The case for the World Health Organization's Commission on the Social Determinants of Health to Address Sexual Orientation, *American Journal of Public Health*, 102(7): 1243-1246.

[4] Irlam, C.B. (2012). *Discussion Paper: Developing an 'evidence-informed' environment for LGBTI policy*. Melbourne: National LGBTI Health Alliance.

[5] See above, n.4, p.9

[6] Krieger, N. (2001). Theories for social epidemiology in the 21st century: an ecosocial perspective, *International Journal of Epidemiology*, 30: 668-677, p. 672.

[7] See: Dane, S.K., Masser, B.M., MacDonald, G., Duck, J.M. (n.d.). *Not So Private Lives: National findings on the relationships and wellbeing of same-sex attracted Australians*. Brisbane: The University of Queensland & PFLAG. Brisbane. See also: Leonard, W. Pitts, M., Mitchell, A., Lyons, A.. Smith, A., Patel, S., Couch, M. and Barrett, A. (2012) *Private Lives 2: The second national survey of the health and wellbeing of gay, lesbian,* bisexual and transgender (GLBT) Australians. Monograph Series Number 86. Melbourne: The Australian Research Centre in Sex, Health & Society, La Trobe University

situation, whereby the maxim "no data, no problem[8]" prevails, with decisions not to include LGBTI Australians in specific policies often resulting from this situation[9]. We argue that this situation represents a historic failure to count LGBTI Australians, which must be urgently rectified. In an international setting, many LGBTI people have died while trying to be counted, including as members of their own families and communities, as a result of a failure to acknowledge and uphold their fundamental rights as *human* beings[10].

We note the need to ensure sensitive and appropriate collection, and subsequent analysis, of data by Commonwealth departments and agencies and suggest that this can be achieved through the formation of either one, or a number, of advisory committees dedicated to improving the collection and quality of data concerning the social determinants of health for LGBTI people. These should ideally be comprised of LGBTI community representatives, researchers, and representatives of government agencies or departments, who could determine the parameters of data collection and practical considerations (notably including privacy) in obtaining data in a range of settings.

The NSW GLRL is of the view that the appropriate collection, disaggregation and reporting of demographic information concerning LGBTI people in the context of health and social service delivery will also assist government departments and agencies to more appropriately target their services and programmes, enable accountability for expenditure on specific services and deliver wider benefits for the Australian community.

Recommendation 1: ***The NSW GLRL calls for the routine collection, reporting and disaggregation of data pertaining to LGBTI people's health and wellbeing, and their underlying social determinants, across Commonwealth Government agencies where these do not currently exist. This may include changes to the guidelines for existing relevant Minimum Data Sets.***

Recommendation 2: ***The NSW GLRL supports calls for increased consultation with LGBTI communities, researchers and community-based organisations in relation to data collection concerns and emphasises the need for training for those soliciting information pertaining to sexual orientation and gender identity.***

Recommendation 3: ***We recommend the formation of either one, or a number, of advisory committees dedicated to improving the collection and quality of data concerning the social determinants of health for LGBTI people. Such advisory committees should be comprised of LGBTI community representatives, researchers, and representatives of government agencies or departments, who could determine the parameters of data collection and considerations in obtaining data in a range of settings, including privacy.***

[8] Krieger, N. (2004). Data, 'race', and politics: A commentary on the epidemiologic significance of California's Proposition 54, *Journal of Epidemiology and Community Health*, 58: 632-633.
[9] See above, n.4, p.9
[10] United Nations (2012). *Born Free and Equal: Sexual Orientation and Gender Identity in International Law.* Geneva: United Nations Office of the High Commissioner for Human Rights.

(D) SCOPE FOR IMPROVING AWARENESS OF SOCIAL DETERMINANTS OF HEALTH

The report of the WHO Commission on the Social Determinants of Health (CSDH) explicitly calls for a paradigm shift in the promotion of health literacy, which traditionally refers to an awareness of risk factors in an *individual's* everyday life, towards an approach that encompasses an equal awareness of the social determinants of health at a population-level. The report states,

> "The understanding of the social determinants of health among the general public needs to be improved as a new part of health literacy[11]"

The term social determinants of health can be understood here to refer to the factors that work either singularly, or synergistically in combination, to shape the health and wellbeing trajectories of specific population groups, including LGBTI people. Accordingly, the WHO CSDH report argues for an expanded concept of 'health literacy' that encompasses "the ability to access, understand, evaluate and communicate information on the social determinants of health", noting that "[t]his requires good, reliable, accessible information tailored to the needs and circumstances of different groups."

Whilst the WHO CSDH report does not explicitly make reference to sexual orientation as a social determinant of health[12], there is a burgeoning body of literature, both within Australia[13] and overseas[14], which points to the ways in which sexual orientation functions as a determinant of health. The NSW GLRL argues that any effort to improve awareness of the social determinants of health within the community, across government programmes and amongst health and community service providers therefore necessarily needs to include an explicit acknowledgement of the way in which sexual orientation and gender identity function as social determinants of health. In accordance with the terms of reference for the inquiry, we provide recommendations pertaining to awareness raising within a number of specific sectors below.

(i) In the community

Efforts to promote awareness of the social determinants of health, including sexual orientation and gender identity, in the broader community are critical to realising the goals of the WHO CSDH report, and other WHO resolutions and publications. The recent *'No To Homophobia'* campaign[15], a collaborative partnership between a range of different LGBTI community organisations, community and mental health service providers, and the Victorian Human Rights and Equal Opportunity

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[11] Commission on the Social Determinants of Health (2008). *Closing the Gap within a Generation*. Geneva: World Health Organisation, p. 189.

[12] Logie, C. (2011). The case for the World Health Organization's Commission on the Social Determinants of Health to Address Sexual Orientation, *American Journal of Public Health*, 102(7): 1243-1246.

[13] Hillier, L., Jones, T., Monagle, M., Overton, N., Gahan, L., Blackman, J., Mitchell, A. (2010). *Writing Themselves in 3: The Third national study on the sexual health and wellbeing of same sex attracted and gender questioning young people*. Melbourne: LaTrobe University. For a discussion of sexual orientation as a determinant of social wellbeing, see also: Kassisieh, G. *"We're family too": The effects of homophobia in Arabic-speaking communities in New South Wales*. Sydney: ACON.

[14] Rossen, F.V., Lucassen, M.F.G., Denny, S., & Robinson, E. (2009). *Youth 07': The health and wellbeing of secondary school students in New Zealand: Results for young people attracted to the same sex or both sexes.* Auckland: The University of Auckland (http://www.fmhs.auckland.ac.nz/faculty/ahrg/_docs/2007-samesex-report-web-02.pdf)

[15] See: http://www.notohomophobia.com.au/

Commission, exemplifies an attempt to heighten awareness of the social determinants of health in the community. In this specific case it does so by using a range of multi-media tools, including an advertisement, focusing on discrimination on the basis of sexual orientation and gender identity as determinants of health and outlining the negative impacts these forms of discrimination exert on individuals and communities. Whilst this campaign is focused at a state level (Victoria), it has a national online presence. The NSW GLRL is of the opinion that a similar campaign, focusing on sexual orientation and gender identity as social determinants of health, should be explored at a Commonwealth level, or that the existing one could be expanded as part of a commitment to increasing awareness of sexual orientation and gender identity as social determinants of health.

(ii) Within government programmes

Sufficient scope exists within existing government programmes to improve the awareness of the social determinants of health. However, it is unlikely that efforts to promote awareness of the social determinants of health will achieve optimal outcomes, unless they are focused and co-ordinated across government, rather than led by the health-sector alone. This is precisely because "policies, interventions and actions outside of the health sector can address determinants of health more directly than they can address health outcomes."[16] For this reason, the NSW GLRL advocates the adoption of a whole-of-government approach to the social determinants of health. We suggest that this could entail, for instance, the formation of an interagency committee, at departmental level, and a Ministerial working-committee within Cabinet, to co-ordinate actions aimed at addressing the social determinants of health, and related driving-forces, shaping population health trajectories. This is a particularly important task in the area of LGBTI health and wellbeing, where a number of disparate concerns, such as school bullying, adult mental health, access to healthcare services more broadly and issues of ageing, arise and where different Ministerial portfolios are implicated in responding to these diverse, but interrelated, issues.

(iii) Amongst health and community service providers

Raising awareness of the social determinants of health, including sexual orientation and gender identity, amongst health and community service providers, requires adequate investment in training for policy and administrative staff, as well as front-line workers. Here, government agencies and other funding bodies have a clear role to play, through supporting services that complement front-line delivery by building an awareness of the social determinants of health[17], which are outside the ambit of healthcare services alone, but exert a considerable influence over population health and wellbeing trajectories[18]. The NSW GLRL suggests that any additional expenditure in this area would

[16] Stahl, T., Wismar, M., Ollila, E., Lahtinen, E., Leppo, K. (2006). *Health in All Policies: Prospects and Potentials*. Helsinki: Ministry of Social Affairs and Health, p. 7.

[17] Such innovative approaches have already been adopted in New Zealand, to enable clinicians and policy-makers to engage with the underlying inequities in healthcare, particularly between indigenous and non-Indigenous New Zealanders, thereby increasing an awareness of the intersection of 'coal-face', or so-called 'proximal' factors, and more macro-level, or 'distal' factors, impacting on health and wellbeing, and what needs to be done to change these**.** See: Signal, L., Martin, J., Reid, P., Carroll, C., Howden-Chapman, P., Ormsby, V.K., Richards, R., Robson, B., Wall, T. (2007). Tackling health inequalities: moving theory to action, *International Journal for Equity in Health*, 6(12): 1-6.

[18] See above, n. 16.

represent an investment in new infrastructures of health, to meet the needs of a growing, and increasingly diversified, Australian population.

In this respect, the NSW GLRL notes with approval the recent decision by the Commonwealth Department of Health and Aging to allocate funding to selected aged care services to improve their ability to relate to, and care, for elderly LGBTI Australians[19], which we argue implicitly recognises the role of sexual orientation and gender identity as determinants of health. These initiatives address identified, and documented, needs relating to LGBTI people in the aged-care sector[20]. We commend the Commonwealth for taking this step and call for the expansion of such measures across the youth health and wellbeing sector(s) as well, in order to build capacity and strengthen the ability of services that address the needs of LGBTI young people, to effectively advocate for improvements to their health and wellbeing at a broader level. This may include efforts to engage in systemic advocacy around the social determinants of health, as envisaged by the WHO CSDH report[21].

Recommendation 4: ***The NSW GLRL recommends that the Commonwealth adopt a whole-of-government approach to promoting awareness of the social determinants of health. This approach should build not only on the report of the WHO Commission on the Social Determinants of Health, but also the burgeoning body of literature from within Australia that demonstrates that sexual orientation and gender identity function as social determinants of health, impacting on the wellbeing of LGBTI individuals and communities across the lifecourse.***

Recommendation 5: ***The NSW GLRL recommends that training on the social determinants of health, and particularly sexual orientation and gender identity, be provided for health and community service providers, including, where relevant, through Commonwealth funding.***

[19] See: http://gaynewsnetwork.com.au/news/northern-territory/7996-funding-for-lgbti-aged-care-projects.html

[20] Spina, A. (2012). *Evaluation Report Addendum: LGBTI Diversity in Aged Care Community Pilot Workshops*. Author: Bondi.

[21] Commission on the Social Determinants of Health (2008). *Closing the Gap within a Generation*. Geneva: World Health Organization, p. 189.