Aged Care for Transsexuals

A Comprehensive Report on Our Unique Needs

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These observations grew out of a pilot workshop organised by the N.S.W. Gender Centre, held at the Harmony Centre at Bundanoon in the Southern Highlands of N.S.W. on 29th-30th March 2010. It was a delightful and restful setting, with comfortable accommodation and wonderful food and set in the delightful gardens of the Centre. The program was perhaps ambitious given the scope of the original design which was not devoted exclusively to aged-care issues. Six transsexuals gathered under the skilful care of Petria King as facilitator, exploring issues of personal growth and wholeness as well as dealing with grief, psychological pain and stress. The sessions on the second day examined specific medical and legal issues facing transsexuals as well as aged-care requirements. No matter how much we may seek to avoid dealing with these issues, not dealing with them will only mean that other people will make decisions on our behalf and those decisions may not lead to the outcomes that we would want.

There are, nevertheless, serious personal, practical, medical, legal, ethical and equity issues that should be considered, affecting not only ourselves but also care providers and indeed government departments at State and Federal levels.

Attending the afternoon discussion on transsexual aged-care was Dr. Michele Chandler, a senior executive from the Riviera Health Group, a privately owned company providing aged-care services in N.S.W.. The Riviera Group has made a corporate commitment to an inclusive policy on the provision of aged-care services for L.G.B.T.I. clients and has opened a residential facility at Katoomba in which inclusive practices are implemented and new residences are currently being planned. Dr. Chandler wanted to hear directly from transsexuals as to specific needs important to them, in the event that they find themselves in a residential care facility.

The active involvement by Riviera Health in transsexual aged-care is a welcome and important development in the aged-care sector, which is currently dominated by institutions either owned by or affiliated with religious denominations.

In the past, these groups have not displayed an inclusive approach to aged-care and in many cases have policies which reinforce the existing heteronormative bias currently found in aged-care. Heteronormativity refers to the assumption by governments and care providers (reflecting wider social and religious prejudice) that all clients will be heterosexual couples or singles, with the consequent invisibility of gender and sexually diverse clients. I will return to this point later.

Although our group was small (six in total; two post-op transwomen and four pre- or / non-op transwomen), the discussion was vigorous and open-ended and presented many issues for consideration by Riviera Health to enable the development of their policies. These related to specific client care issues that are very relevant for managers like Dr. Chandler. I will also briefly refer to more general issues relating to transgender health.

Being gender variant itself is not a risk factor for poor health or wellbeing. Unfortunately discrimination experienced by people whose gender identity does not match their biology often exposes transgendered people to harmful experiences, and compounds the effects of various risk factors in their lives including violence, isolation, high rates of anxiety and depression, suicide, homelessness, unemployment, substance abuse, unsafe sex practices and exposure to transmissible infections.

There is a pressing need in Australia for the development of standards for co-ordinated multi-disciplinary assessment and treatment in the provision of aged-care services for transgendered people.

Key Principles For Transgender Aged-Care

- Be respectful to transgender identity;
- Be responsive to specific medical issues relevant to transsexuals;

- Provide support for transsexuals and transgendered people who are not able, for various reasons, to access gender affirming surgical or medical care;
- Be supportive of the spouses and partners of transsexuals, including same-gender partners;
- Provide support for the cultural needs of clients (viz. community information sources including online services, community periodicals such as *Polare* and magazines of relevance to L.G.B.T.I. interests;
- Actively support information and linkages to community support organisations and their activities; and
- Ability to offer residents a choice of appropriately qualified and experienced primary and specialist medical providers who can effectively care for the health of transgendered clients.

Providing Aged-Care For Transgendered Clients

On first reading, these ideal principles may seem bland. They translate, however, into management practices and highlight care issues for the providers of aged-care services that are very important for transsexuals and transgendered clients generally.

Admission Questionnaires

It is critical that admitting clients be allowed to indicate their innate gender identity (or none), personal name and preferred style of address as part of their routine admissions process. Questionnaires are usually used to direct management in relation to the care needs of individual clients. This may be important for individuals whose gender identity and style of presentation do not match their anatomy or legal status (i.e. gender non-congruent).

Some transsexuals or other transgender clients may not be able (or wish) to access medical or surgical procedures and as a consequence may not live fulltime in their innate (rather than assigned) gender.

The admission questionnaire, if designed appropriately and administered professionally, is a critical part of the management of individual care needs.

Respect for Transgender Identity

At its core this begins with the recognition and acceptance that individuals' identities are what they say they are, regardless of their appearance, and they deserve to be known and addressed as and referred to by their preferred names and appropriate pronouns etc. This is as true for transgendered clients who have not been able to access gender affirming surgery as it is for post-operative transsexuals. For women this also means appropriate personal grooming such as nails, hair/wigs, make-up and clothing. Some transwomen will have issues with facial and body hair and male pattern baldness, especially where they transitioned late and have not had the resources to fund permanent hair removal or hair transplants.

In providing personal care (in showering for instance) staff need to respect the client and, for example, refer to her by her female name even though she has male pattern baldness (without her wig) and male genitals.

Very important for many post-operative transwomen is dilation, which enable them to maintain a functional vagina. This will be important for many post-operative women, regardless of whether they have a partner, for their own sense of femininity and completeness. While still able, transwomen will usually dilate themselves.

When a woman becomes infirm but still wishes to retain her vagina, however, staff will need to undertake this task to an agreed schedule along with other personal care needs. This will require considerable sensitivity and training on the part of residence staff. It also means that transwomen will need ongoing supplies of medical lubricant and access to washing facilities for the dilators and to be able to douche after each session. It is important that transwomen have adequate privacy to enable them to dilate, and secure storage facilities for dilation kits.

Some non-operative transgender people identifying as women may seek varying degrees of hormonal intervention to alter their appearance without impacting on their male sexual function.

Many transsexuals are rejected by their families and peers and in consequence place increasing reliance on friends and informal networks as well as transgender support organisations in their local areas. It is important that care providers recognise and support these informal networks. Closer linkages should also be fostered by care providers and transgender support organisations to provide social and other support activities for transgender clients.

Provision of transgender community information, magazines and periodicals

Periodicals and magazines from transgender organisations should be available for transgendered clients in nursing homes, as a means of creating a more familiar environment as well as providing community news and information about community activities. The journal of the N.S.W. Gender Centre, *Polare*, is an important source of community events and news of interest to transsexuals, as is *Torque* magazine and the website F.T.M. Australia for transmen. There are also other community newspapers and magazines of special interest to L.G.B.T.I. people generally, such as *Sydney Star Observer*, *Cherie*, *L.O.T.L.* etc.

Training of residential care staff

Staff from residential care facilities will need professional training in best practice at providing care to transgendered clients. The most important focus of the training should be to promote understanding and respect for transgender identity: to help staff to accept, for instance, that the elderly, frail, balding man in room number eight is called Shirley and that her gender identity is female.

When Shirley's boyfriend, Ben, comes to visit her, they are not two men holding hands but the male partner of a woman with a

transgendered history visiting his partner.

It will be obvious from the foregoing and from the discussion of specific medical needs for transsexuals, that it would not be sufficient for staff training to focus on L.G.B. issues alone, although they, too, are important.

This may be a challenge to management, not only in providing suitable staff training, but also in coping with staff unwilling to perform functions such as dilation, particularly if they feel they may be subjected to increased risk of being accused of sexual abuse by the transsexual client or by other residents. There may also be staff for whom performing such tasks raises difficulties with their religious or cultural beliefs.

Best practice would suggest that transgender support organisations be invited to participate in the design of staff training courses, and perhaps in conducting part of the training on behalf of the management.

Transgender Advocates in Aged-Care

Where conflict or disturbances occur in aged-care residences the assistance of a transgender advocate may be beneficial. These conflicts may include conflict with other residents, or over an issue regarding medical treatment or care, or indeed an issue between the resident and his/her family. The advocate does not need to be transsexual, but should be someone who is a good listener and a good communicator and who has the negotiating skills to be able to support the interests of a resident where gender identity is a factor.

The person best suited for this role might be someone from a transgender community support organisation. It would not be sufficient to assume, for example, that a person from an L.G.B. community organisation would automatically be experienced in dealing with transgender issues.

The staff at the nursing home may well initiate contact with the advocate if they believe, for example, that the family is being overbearing or attempting to bully the client with regard to gender presentation, medical or other issues e.g. denial of spousal rights to partners.

The transgender advocate is not intended to duplicate, in any way, the role of the person for whom enduring guardianship rights have been accorded, in relation to medical decision making.

In States other than N.S.W. this role is sometimes referred to as Enduring Medical Power of Attorney.

Medical Care for Transsexuals

Residential care providers are very familiar with meeting clients' medical needs, but there are particular needs for transgendered clients which may not be as familiar to care providers. Indeed the current younger generation of transsexuals (eighteen to thirty-year-olds) is likely to be the first to test the effects of lifetime cross-sexed hormone replacement therapy (H.R.T.) on transgendered clients. At present there are no data on the long-term effects of H.R.T. on either post-operative or non-operative transwomen or transmen. This is in stark contrast to the extensive and complex clinical trials conducted in a number of countries to examine the effects on natal women of H.R.T. used to alleviate the symptoms of menopause.

Specific Medical Needs

For transwomen, and despite the suppressive effects of oestrogen, progesterone and androgen blockers on male sexual organs, there remains a low but identifiable risk of prostate cancer. Non-operative transwomen will also need access to other urological services such as screening for testicular cancer.

The risk of breast cancer is a function of lifetime exposure to oestrogen. It is assumed that the longer a transwoman receives H.R.T., the more closely the risk of breast cancer approaches the risk profile for natal women.

For transmen, the risk of endometrial (lining of the uterus) and other cancers is significant with lifetime testosterone-based H.R.T., especially where those men have not had 'bottom surgery' for the removal of their uterus, ovaries and fallopian tubes. Transmen will have an ongoing need for Pap smears (testing for the presence of cervical cancers), and transmen who have not had 'top surgery' (bilateral mastectomy) may also need regular breast screening services.

On the other hand, for both transwomen and transmen, ceasing H.R.T. may lead to increased risk of 'brittle bones' (osteoporosis) and consequent fractures, especially where there is an increased risk of falls because of reduced mobility and impaired sense of balance associated with ageing.

Because oestrogen has a protective effect on cardiac health, transwomen may experience an increased risk of cardiac problems when ceasing H.R.T., similar to post-menopausal natal women. After menopause with falling levels of oestrogen, the cardiac risk profile for natal women is similar to that for men.

Regardless of operative status, all transsexuals receiving ongoing H.R.T. will continue to need regular blood tests in old age (typically six monthly). This raises an issue for care providers. All transgendered clients in some form of residential care will need access to G.P. and specialist services from medical staff experienced in the special needs of transgendered people. Locating such experienced professionals may become difficult, especially where elderly transsexuals are not mobile and unable to visit clinicians in their offices. This is a significant problem for transgendered clients living in regional and rural Australia but it is also an important issue for residential aged-care providers with frail elderly transgendered clients, regardless of location.

Unfortunately, from my experience, broadly based knowledge of transgender medical needs and appropriate treatment regimes cannot be presumed within the general community of primary care providers (G.P.s) nor in the public hospital system. This is a much wider issue relating to professional medical education, when addressing the needs of transgendered patients.

Medicare rebates

At the present time, this is a vexed administrative issue. Transsexuals, post-op and non-op, are likely to experience difficulties with Medicare procedure numbers, because many specific procedures that are relevant, for example, to the early detection of cancers, are sex linked.

Thus post-operative transsexuals, women and men whose changed sex status has been legally recognised within Australia, are likely to encounter difficulties with Medicare procedure schedules.

Women don't possess a prostate but if we require surgery or medication later in life (yes, transwomen do experience prostate cancer), and if our sex status with Medicare is consistent with our legal status i.e. has been changed from assigned to affirmed, then some creative accounting may be necessary to allow the Medicare claim to be accepted. Similarly, for example, men don't have a uterus or cervix. Post-operative transmen may require regular Pap smears for the early detection of cervical cancer.

Non-operative transsexuals or other transgendered people who are unable to change their legal status may encounter other difficulties. Non-operative transwomen for example are unlikely to be able to access regular breast screening services, even though they may have been on H.R.T. for many years and are therefore at risk of breast cancer.

Prevalence of Transsexualism

Aged-care providers are likely to be interested in the extent and prevalence of transsexualism in Australian society. A major difficulty is, however, the absence of hard data in Australia on this question. A number of studies have, however, been conducted overseas, beginning in 1965.

The most frequently cited report is the 1993 study from the Netherlands which was based on those presenting for hormone therapy and gender affirmation surgery. This study reported a prevalence of 1:11,900 for transwomen 1:30,400 for transmen (Bakker, van Kesteren, Gooren and Bezemer, cited by Nesteby, J., Transgender health; a resource for primary care providers, Massachusetts General Hospital Institute of Health Professionals, 2007). This is likely to underestimate significantly the number of transsexuals in Australia, let alone the number of people who may identify as transgendered.

This prevalence standard is currently used as a benchmark by the World Professional Association of Transgender Health (W.P.A.T.H.) which was formerly known as the Harry Benjamin International Gender Dysphoria Association (H.B.I.G.D.A.).

A more recent Australian study (2005) cites 'guesstimates' based on different prevalence rates for transsexualism of 1:10,000. Sinnott, V. Best practice models for the assessment and care of transgender people and people with transsexualism. A discussion paper for Victoria, Melbourne 2005. p.2.

In 2007, Olyslager and Conway extensively re-examined the data from these earlier studies (from 1965 through to 1997) and using mathematical models have attempted to derive prevalence and incidence data for transsexualism and the likely prevalence of the population who identify as transgendered (Olyslager, F. and Conway, L., 2007. On the calculation of the prevalence of transsexualism, a paper presented at the W.P.A.T.H. Twentieth International Symposium, Chicago, Illinois, 5th-8th September 2007).

An important conclusion from their analysis is that for each study from 1965 onwards, the prevalence data has been progressively revised upwards. They correctly point out that this needs to be explained and propose that the medical and surgical treatment for gender incongruence or gender dysphoria in those Northern European countries and Singapore where the studies were conducted, was 'in a start-up transient'.

This conclusion appears to be compelling for a number of reasons. Simply put, there appears to be a convergence between improvements in medical and surgical technology and more recent information technology, which has not only led to improvements in treatment outcomes for transsexuals, but which has also allowed a much greater knowledge by transsexuals, parents and society generally of these improvements. This has been paralleled in many countries by government measures banning discrimination against transgendered people, and by the legal recognition of 'change of sex'.

Olyslager and Conway propose that, based on their analysis, the prevalence of transsexualism is 1:2,000 of the population for transwomen and 1:4,500 for transmen. These conclusions are based on data from the earlier studies counting primarily transsexuals presenting for clinical intervention, either seeking help variously, from psychiatrists, or through H.R.T. and/or gender affirming surgery. I believe this data is closer to the 'real' prevalence of transsexualism. Less convincing in my view is when they go further by suggesting an even higher 'lower bound' for the prevalence of 'inherent' M.T.F. transsexualism (transwomen) is 1:500 and for 'transgender prevalence' is 1:100. These higher figures depend on the mathematical modelling, which in turn depends on assumptions which may be difficult to sustain.

Nevertheless, the lower prevalence conclusions (1:2,000 and 1:4,500) translate into much higher numbers of transsexuals than previously envisaged. Population data from the N.S.W. Department of Ageing, Disability and Home Care, Office for Ageing Fact Sheet October 2007, shows total H.R.T. population in 2006 at 6,843,900 and projected to increase to 8,259,200 by 2031.

Using the Olyslager-Conway prevalence data, this means in 2006 there were 4,943 transsexuals in N.S.W., which are projected to increase to 5,965 in 2031. (These data include transmen as well as transwomen.)

The N.S.W. population aged sixty-five and over in 1996 was 942,300 rising to 1,812,600 by 2031. This translates into 680 transsexuals over sixty-five in N.S.W. in 1996, increasing to 1,309 transsexuals over sixty-five in 2031.

General Transgender Health and Wellbeing

The prospect of needing residential aged-care is likely to generate high levels of anxiety and a sense of threat to the wellbeing of many transsexuals. This applies equally to transmen as it does to transwomen. They will both face the prospect of being involuntarily 'outed', even if they have been passing successfully in their innate gender roles.

It is conventional wisdom among the older generation of transwomen that approximately ninety percent are not passable. This is largely a function of the age at which they began to transition. The irreversible effects of testosterone, particularly on the skeletal frame are impossible to surmount, even with modern reconstructive surgical techniques.

Transwomen who transitioned in their twenties and who have lived as completely passable women, may find themselves involuntarily 'outed' in residential care if they need to dilate. Similarly, transmen, who have successfully lived for years as men, may suddenly discover their gender incongruence is exposed when needing assistance with personal hygiene.

There is a range of health and wellbeing issues affecting transgendered people, specifically as they age:

- Invisibility in the general aged-care sector at the present time;
- Ongoing gender identity and sexual orientation discrimination in institutionalised aged-care, which reflects the current widespread heteronormativity of gerontology and policy planning in aged-care;
- Ageism within transgender communities as with L.G.B.T.I. communities generally;
- Exclusion from youth orientated L.G.B.T.I. social networks.

Key Social Determinants of Transgender and Wellbeing

Socio-Economic Status

Socio-economic disadvantage is a powerful predictor of poor health. For transgender people, loss of income during transition is commonplace. TransGender Victoria estimates that 95 percent of its members have been forced to give up their jobs during gender-reassignment.

Ethnicity

Little work has been done on the manner in which ethnic differences interact with gender identity and sexual orientation. In many ethnic groups, transgendered people are rejected by their families and as a consequence may experience isolation and loneliness. In other cultures family pressures are so strong that transgendered people are forced to submit to cultural norms and marry to continue the family name, ensuring that many live divided lives.

Indigenous Australians have significantly higher rates of mortality and illness than the general population. This may be due to cultural differences and to reduced standards of care resulting from racial discrimination and insensitivity within the health care system.

In contrast, many indigenous cultures have culturally sanctioned initiation rites and ceremonies which recognise individuals' transgendered status as women and which accords a culturally sanctioned place for male homosexuals (initiated as both men and women).

Gender Inequality

Women's health and wellbeing are inextricably linked to their position in society. Women are primary caregivers, have lower rates of income than men and suffer more domestic violence. Research indicates that gender and gender-inequality influence health issue specific to lesbians, including patterns of illness and reduced access to standards of care.

Gender inequality is also likely to play a role in the health issues specific to transwomen, especially older transitioners who may encounter difficulties associated with the loss of male privilege and accompanying lower social status.

Geographic Location

There is little systematic research that looks at variations in transgender health across different geographic locations. Anecdotal reports suggest that the following factors may contribute to poorer health outcomes in rural and regional Australia. These include:

- Fewer health service providers with knowledge and expertise in transgender health issues;
- Increased levels of transphobia and homophobia generally;
- Reduced access to The Matrix Guild of Victoria community and support networks.

Disability

Transgender people living with a disability may be subject to the combined effects of transphobia and homophobia as well as discrimination directed against people with a disability.

For example, a disabled lesbian transwoman may not feel welcomed within a disability support network, nor within the lesbian community generally.

Carer Support

There are also support issues for transgendered people caring for partners, friends or relatives with a disability. Frederickson (1999) in

a study examining care giving responsibilities among gay men and lesbians found that 32 percent of gay men and lesbians were care givers: Lesbians are more likely to be caring for children and elderly people and gay men more likely to be assisting working age adults with a disability.

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The Gender Centre is committed to developing and providing services and activities, which enhance the ability of people with gender issues to make informed choices. We offer a wide range of services to people with gender issues, their partners, family members and friends in New South Wales. We are an accommodation service and also act as an education, support, training and referral resource centre to other organisations and service providers. The Gender Centre is committed to educating the public and service providers about the needs of people with gender issues. We specifically aim to provide a high quality service, which acknowledges human rights and ensures respect and confidentiality.