We Don't Have That Kind of Client Here: Institutionalized Bias Against and Resistance to Transgender and Intersex Aging Research and Training in Elder Care Facilities

Lisa Belongia[1] and Tarynn M. Witten[2†]

[1]Department of Rehabilitation Counseling

[2]Departments of Social Work and Gerontology

Virginia Commonwealth University

and

TranScience Research Institute

In a series of articles, Witten (2002; 2003; 2004) and colleagues (Witten & Eyler, 1999; Witten & Whittle, 2004) have documented the problems of individuals who are transgender-identified and/or intersex-identified coincident with being elderly. They pointed out and subsequently elaborated upon both the problem of invisibility and of being a simultaneous member of multiple out-groups (aging and transgender/intersex), not to mention how those memberships and their associated emergent difficulties can be further exacerbated by memberships in other more traditionally identified minority/diversity groups such as race, ethnicity, and socio-economic status.

Recently Zlotnick, Vourlekis & Galambos (2006) discuss the importance of improving psychosocial care in nursing home settings. They also present some of the upcoming challenges to addressing this problem area. In addition, they point out that such improvements, in our

[†] Address all communications to this author at the following address: Tarynn M. Witten, PhD, CSBC, VCU, PO Box 842030, Suite 111, 1000 West Cary Street, Richmond, VA 23284-2030. Email: twitten@vcu.edu. For more on aging issues in the transgender and intersex population, see http://www.transcience.org/

nation's over 17,000 nursing facilities, would lead to overall advances "in quality of care for nursing home residents and support the development of more effective and efficient monitoring and quality improvement strategies … Zlotnick, Vourlekis & Galambos (2006)."

Given the well-documented fact that the U.S. population demographics will continue to increase in total number of aging persons (*e.g.*, Yali & Revenson, 2004) and given the fact that healthcare disparity in minority populations is considered a major public health issue (Smedley, Stith & Nelson, 2003; Victoria, 2006), it is natural to assume that, from a Public Health perspective, all of the traditional diversity aging population groups are being dealt with. However, a number of population groups having significant prevalence, continue to remain invisible with respect to the organizations that deal with services to the aged and, as such, remain invisible to important public health organizations and their policy plans (Witten, 2002; 2003). In particular, we point to the general invisibility of the transgender-identified and intersex-identified populations due to the more recently documented phenomenon of invisibilization by staff members of eldercare healthcare facilities.

Both Witten and Eyler (1999) and Witten (2003) have pointed out that the number of elder persons who identify as transgender, transsexual or intersex has not been well-documented. The primary barrier to determining the demography of these populations arises from a number of factors. First is the inconsistent understandings of the terms "sex" and "gender" within the Western biomedical environment, where these two terms are (incorrectly) used interchangeably (Witten, 2004; 2005). In particular, the predominant model for gathering demographic information offers two choices of identifying one's sex, male or female, but most commonly asks

for a person's gender. Such a model clearly invisibilizes persons who may identify as non-normatively sexed or gendered (Witten, 2003) or as non-Western gender identities (Witten *et al*., 2003; Witten, 2004). Thus, there is a fundamental disparity in research and data gathering concerning transgender- and intersex-identified public health dynamics and this disconnect results in an automatic marginalization of intersexed, transsexual and transgendered persons. More importantly, the lack of information about trans/intersex-identified elderly causes many institutions to believe that they do not need to be concerned with serving those populations due to the fact that, "we do not have anyone like that in our facility."

Our recent attempts to conduct a study in the long-term care setting have revealed yet another barrier to research in support of the transgender/intersex-identified elder populations: the profound unwillingness of administrators to allow their facilities to participate, as well as a seemingly entrenched belief that their facilities would never have to deal with such issues.

This discovery occurred, by virtue of a recent attempt to develop an in house training program to educate nursing home staff around issues of transsexual and transgender eldercare. This project was part of a larger study designed to examine the following three questions: (1) Do nurses and social workers in nursing homes have experience working with transgender, transsexual and intersex patients? (2) Does a bias exist among nurses and social workers in nursing homes or other elder-care facilities against working with transgender, transsexual and intersex patients? And, (3) does cultural competency training for nurses and social workers increase awareness of issues specific to working with elder transgender, transsexual and intersex patients?

The authors contacted Directors of Nursing, Social Work supervisors, and nursing home administrators at major facilities and asked them to participate in a one-hour training course on cultural competency concerning care of transgender- and intersex-identified elders. We implemented a pre/post test design in which we planned to administer brief questionnaires before and after the training. The questions focused on ascertaining the impact of cultural competency training on attitudes of nurses and social workers. No identifying information was to be gathered.

Twenty-nine facilities that were contacted and only two agreed to participate (6.9%). Five facilities formally declined (17.2%), and the remaining twenty-two (75.9%) did not respond to repeated requests (telephone, fax, and follow-up visitation) to participate. The social worker at one of the two accepting facilities was a former student of one of the authors and was interested in the subject. Of the five facilities who declined, four (80%) responded that the topic was not relevant to their patient population, and the remaining Director of Nursing did not understand the term transgender. In fact, she had the misperception was that transgender was "a homosexual thing." The telephone discussion with this particular Director of Nursing was heated. Her disapproval of the topic was quite evident, and she refused to reconsider her position that "these people" are not part of her patient population. The conversation ended with the Director of Nursing abruptly hanging up. Discussions with the other four facilities, though more civil in tone, were of the same nature. All four facilities insisted that this was not a relevant topic for their patient population, and refused to consider data that might suggest otherwise. The common institutional response seems to be a firm belief that "these people" are not ever patients in nursing homes or other eldercare facilities. Therefore, learning about their particular needs is

unnecessary. Additionally, we found that there is a tendency to link transgender and intersex identities with homosexuality, rather than recognizing the important distinction between the concepts of sexual orientation, gender identity and expression, and chromosomal/anatomical birthsex (the birth body, Witten, 2003; 2005).

During the IRB approval process, gaining approval from nursing facilities to present the training significantly delayed the final IRB decision. In addition, a further hurdle was encountered. The IRB requested that the submission for approval be amended to include potential risks and risk reduction "given the sensitive nature of information gleaned from the questionnaires." Multiple requests for clarification from the IRB regarding their understanding of the potential risks only resulted in further questions about the exclusion of special cases. Of particular concern to the IRB was the potential harm of this study to pregnant women. The responses of both the IRB and the elder care facilities left the investigators with the impression that this competency training was considered a highly sensitive and potentially harmful issue. This suggests that there exists a strong bias against research and/or a lack of knowledge concerning the transgender and intersex populations. Further, it appears that there is a tendency to link transgender and intersex patients with homosexuality, rather than recognizing the very different concepts of sexual orientation and gender identity and expression. In addition to what could be considered an overreaction to the sensitive nature of the topic, the common response seems to be a firm belief that "these people" are not ever patients in nursing homes, and therefore learning about their particular needs is irrelevant. This suggests the potential need for competency training for IRB committees in the transgender/intersex area.

While the overall prevalence of transgender-identified individuals is unknown, Witten (2002) estimates that there are between 350,000 and 1 million transgender persons in the United States who are aged 65 and older. Further, she points out that, based upon known estimates of intersex prevalence, about one out of every 2000 seniors will identify as intersexed (ISNA, 2006). As the number of elderly persons seeking care in nursing home facilities increases, so too will the number of transgender-, transsexual- and intersex-identified individuals. In addition, Witten (2003) reports that many male-to-female transgender-identified individuals "come out" late in life. This automatically classifies them as elder community members. There is a wide age distribution in the transgender and intersex communities. In the transgender community, younger persons (under the age of 18) are coming out as transgendered. This highlights the need for a long-term comprehensive understanding of the needs of aging transgendered persons. Providing culturally competent care to this population mandates that health care providers recognize the social context of their transgender, transsexual, and intersex patients. It also requires that Public Health individuals be aware of the general construct of invisibility as a type of Public Health disparity along with its consequent implications for Public Health issues around transgender/intersex healthcare in general and aging in particular.

Given the potential for negative past experiences with the health care profession (Witten, 2004), it is reasonable to assume that elderly intersex, transgender and transsexual persons will approach their entry into a long term care facility with apprehension (Witten, 2002). While these individuals will enter the long term care facility with the normal issues associated with aging, they will also bring with them particular issues related to their identity as transgendered, transsexual or intersex persons. These issues are complex and have evolved over the lifecourse

(Witten, 2004). In addition, may issues may revolve around the more immediate late-life/end of life issues (Witten, 2007) or around facilities related issues such as being in jail or in a military facility (Witten, 2006). There are many medical considerations particular to this population that must be addressed, including current and past history of hormonal supplementation and surgical procedures such as breast or genital reconstruction that may have been performed (Witten, 2002; Witten and Eyler, 2007). In the case of intersex persons, such procedures may have been imposed upon them at birth, causing a lifetime of attempting to conform to a gender identity and sexuality that may or may not be congruent with who they know themselves to be. These elderly persons may have complicated family relationships and even more complicated legal issues with regard to legal marriages after gender reassignment surgery (Witten, 2007). Elderly transgender, transsexual and intersex patients who enter long-term care facilities have very likely experienced violence, harassment, employment discrimination and physical abuse (Witten and Whittle, 2004).

Trans-elders and intersex elders are resilient people who deserve caregiving that respects their individual life history and that addresses their particular psycho-social and biomedical needs. Given the current limited exposure of healthcare workers to this population, additional research and training in cultural competency is imperative for Public Health and other healthcare workers in the elder care setting.

1. Intersex Society of North America (ISNA). 2006. http://www.isna.org/
2. Smedley, B.D., Stith, A.Y., and Nelson, A.R. (eds.) 2003. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Washington, D.C.: National Academies Press.

3. Victoria, C.G. 2006. The challenge of reducing health inequalities. *American Journal of Public Health*, 96(1): 10.
4. Witten, T. M. 2002. Geriatric care and management issues for the transgender and intersex populations. *Geriatric Care and Management Journal,* 12(3), 20 – 24.
5. Witten, T.M. 2003. Transgender aging: An emerging population and an emerging need. *Review Sexologies*, XII (4): 15-20.
6. Witten, T.M. 2004. Issues of transgender and intersex middle adulthood life course analysis: the courage to search for something more: middle adulthood issues in the transgender and intersex community. *Journal of Human Behavior in a Social Environment*, 8(3-4), 189-224.
7. Witten, T.M. 2005. Birth Sex is Not Gender. Comments on "Efforts to address gender inequalities must begin at home." *The Lancet*, 366 (9496): 1505. http://www.thelancet.com/journals/lancet/article/PIIS0140673605676052/comments?action=view&totalComments=1
8. Witten, T.M. 2006. Gender Identity and the Military – Transgender, Transsexual and Intersex-identified Individuals in the Armed Forces – Part 1. *Center for the Study of Sexual Minorities in the Military, University of California, Santa Barbara*. http://www.gaymilitary.ucsb.edu/. Extended report available at http://www.transcience.org/.
9. Witten, T.M., Benestad, E.E.P., Ekins, R.J.M, Ettner, R., Harima, K., King, D., Landén, T.M., Nodin, N., P'yatokha, V., & Sharpe, A.N. 2003. Transgender and Transsexuality. (in) Ember, C.R. & Ember, M. (eds.) *The Encyclopedia of Sex and Gender: Men and Women in the World's Cultures*. New York, N.Y.: Kluwer/Plenum.

10. Witten, T.M. 2007. End-of-Life Concerns for Transgender Elders and Their Caregivers: Graceful Exits. American Society on Aging, *Outward*, to appear. Available as a free download at http://www.transcience.org/.
11. Witten, T.M. and Eyler, A.E. 1999. The crimes against the transgendered: an invisible problem. *Peace Review,* 11(3), 461-468.
12. Witten T. M. and Whittle, S.P. 2004. TransPanthers: the graying of transgender and the law. *Deakin Law Review,* 9(2), 503-522.
13. Witten, T.M. and Eyler, A.E. 2007. Transgender gerontology and geriatrics: towards successful aging. To appear in: *Principles of Transgender Medicine and Surgery, Haworth Press, 2007.* Available as a free download at http://www.transcience.org/.
14. Yali, A. and Revenson, T. 2004. How changes in population demographics will impact health psychology: incorporating a broader notion of cultural competence into the field. *Health Psychology*, (23) 147-155.
15. Zlotnick, J., Vourlekis, B. and Galambis, C. 2006. Improving psychosocial care in nursing home settings: The next challenge. *Health and Social Work*, 31(2): 83-86.