National Coalition *for* LGBT Health

An Overview of U.S. Trans Health Priorities:

A Report by the Eliminating Disparities Working Group
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This overview is based upon a meta-analysis of the available research on U.S. transgender populations, not all of which has been published in journals. One of the major goals of Healthy People 2010 was the elimination of disparities and outcomes in health care access, and therefore the issues contained herein are classified within the Healthy People 2010 categories. Many of the following issues are inter-related, and most are related to access to health care – to Trans Health services, behavioral health services (including substance abuse treatment and smoking cessation treatment), HIV/AIDS/STD care, and routine health and wellness care. Please note that this report does not include Intersex Issues (see End Note).

1. ***Violence and Murder Prevention*** – (HP2010 Category: Injury and Violence Prevention)
There is sufficient evidence to document the existence of an epidemic of violence directed against transgender people in the U.S., especially transwomen of color. In her review GenderPAC's 1997 anti-violence report (Wilchins et al., 1997) Lombardi found that 27% of its sample had been victims of violence. For the past eight years, San Francisco transactivist Gwen Smith has collected reports of murdered transgender people and those who have died by malevolent neglect through her Remembering Our Dead project (Gender Education & Advocacy, 2004). A statistical report using data from Remembering Our Dead (Helms, 2003) found widespread violence in the U.S with reported murders in 20 states and 89 cities. Several urban needs assessment and risk behavioral studies also report high levels of hate and domestic violence and crime victimization (ActionAIDS et al, 1997; Clements et al, 1999; McGowan, 1999; Xavier, 2000; Kenagy & Bostwick, 2001; Reback et al, 2001; Risser & Shelton, 2002). Distrust of police and the criminal justice system, combined with fears of secondary victimization, result in significant under-reporting of acts of violence or crime committed against transgender people.

2. ***HIV/AIDS and other STD Prevention and Treatment*** – (HP2010: HIV/AIDS & Sexually Transmitted Diseases)
Findings from various needs assessment and behavioral risk studies have reported HIV prevalence in transgender women as ranging from 14% in San Juan (Rodríquez-Madera & Toro-Alfonso, 2000); 19% in Philadelphia (Kenagy, 2002); 21% in Chicago (Kenagy & Bostwick, 2001); 22% in Los Angeles (Simon et al, 2000); 21% to 30% in New York (McGowan, 1999); 27% in Houston (Risser & Shelton, 2002); 32% in Washington, DC (Xavier, 2000); and 26%, 35% and 47% in San Francisco (Nemoto et al, 2004; Clements et al, 2001; Nemoto et al, 1999). Transgender women sex workers are at particularly high risk, since they are often financially induced to engage in barrier-free sex (Boles & Elifson, 1994; Nemoto et al, 1999; McGowan, 1999; Nemoto et al, 2004). A study of transgender sex workers in Atlanta funded by the CDC found a 68% seroprevalence rate (Elifson et al, 1993). Although significantly under-examined, HIV prevalence in transgender men was found to be 3% in Washington, DC (Xavier, 2000) and 2% in San Francisco (Clements et al,

2001). There is also evidence to suggest that male-to-female transyouth of color may be disproportionately impacted by the AIDS epidemic in the U.S. (Sausa, 2003).

3. ***Substance Abuse Prevention and Treatment*** – (HP2010: Substance Abuse)
Significant substance abuse has been identified as a major concern in studies conducted of transgender populations in Atlanta (Boles & Elifson, 1994); Boston (Mason et al, 1995); San Francisco (Clements et al, 1999; Nemoto et al, 1999); New York (McGowan, 1999); Los Angeles (Reback & Lombardi, 1999; Reback et al, 2001) Washington (Xavier, 2000); San Juan (Rodríquez-Madera & Toro-Alfonso, 2000); Chicago (Kenagy & Bostwick, 2001); and Houston (Risser & Shelton, 2002). Obtaining treatment for substance abuse has proven to be largely problematic for reasons that include provider hostility and insensitivity; strict gender segregation (male/female) within programs that result in excluding transgender persons; the lack of welcoming gender-appropriate recovery groups; and hormone use being regarded as "drug use" by some programs, requiring clients to stop hormone use to access treatment (Mason et al, 1995; Clements et al, 1999; JSI, 2000; Lombardi & van Servellen, 2000; Leslie, Perina, & Maqueda, 2001).

4. ***Depression, Suicidal Ideation and Suicide Prevention*** – (HP2010: Mental Health & Mental Disorders, and Access to Quality Health Services)
Studies of transgender populations in Philadelphia (ActionAIDS et al, 1997; Singer et al, 1997) Washington (Xavier, 2000) Chicago (Kenagy & Bostwick, 2001) San Francisco (Clements-Nolle et al, 2001; Nemoto et al, 2002) and Houston (Risser & Shelton, 2002) have reported suicidal ideation rates as high as 64% and suicide attempt rates ranging from 16% to 37%, with most attributing their ideation or attempts to their gender identity issues. Obtaining mental health care is problematic because of discrimination-induced poverty, lack of insurance and the lack of therapists experienced in working with transgender clients (ActionAIDS et al, 1997; Singer et al, 1997; JSI, 2000; Nemoto et al, 2002)

5. ***Lack of Health Insurance and Underinsurance*** – (HP2010: Access to Quality Health Services)
High rates of joblessness and poverty in transgender populations, especially those of color and trans youth, often result in a lack of health insurance or underinsurance (McGowan, 1999; Xavier, 2000; Risser & Shelton, 2002). This results in lack of routine screening for high blood pressure, heart disease, cancers, STDs and other illnesses, increasing the overall morbidity rates of transgender people and likely lessening their life spans (Xavier et al, 2004). There also is anecdotal evidence suggesting that even post-operative transsexual men and women may be unable to keep or obtain health insurance if their transsexual status is revealed to their insurers.

6. ***Lack of Health Insurance Coverage for Trans Health Services*** – (HP2010: Access to Quality Health Services. However, these services are not specifically recognized in HP2010 as medically necessary).
Trans Health services such as transgender hormonal therapy and sex reassignment surgery are commonly excluded by nearly all U.S. health care insurers (Middleton, 1997; JSI, 2000), although Medicaid and VA coverage is or has been available in some states. These blanket exclusions in policies result in significant barriers to access, since many cannot afford the out of pocket expensive costs of these services. Even insured patients are placed in an awkward position with their providers, who often must use nonspecific diagnostic and procedural codes in order to receive

reimbursement for their services. Providers who are not comfortable doing so may simply refuse to work with transgender patients.

7. ***Gender Identity Disorder (GID) as the Principal Diagnostic Means Determining Access to Trans Health Services*** – (HP2010: Access to Quality Health Services and Mental Health & Mental Disorders)
Self-admission of GID (American Psychiatric Association, 1994) – a stigmatizing mental disorder – has long been criticized as a prerequisite to access to Trans Health services (Califia, 1997; Meyerowitz, 2003). Thus an appropriate medical diagnosis sufficient to replace GID has been long sought-after goal by Trans Health advocates. While a few urban, community-based health care organizations have developed their own local Trans Health protocols that do not require a prior GID diagnosis (San Francisco Department of Health, 2003), there is a great need for more such programs that avoid GID as a requirement for access.

Additionally, the diagnosis of GID is often associated with an extended evaluation process that poses an additional barrier to access. Mental health providers are required to act as gatekeepers for referral to hormonal therapy and surgery, and some providers may arbitrarily decide their clients are not qualified for care after a significant period of time and expense by the clients (Lev, 2004; Meyerowitz, 2004). With limited training and/or experience working with transgender clients, most psychiatrists and many psychotherapists tend to interpret GID very narrowly. They often refer clients for hormonal therapy only if they fit a very narrow definition of transsexualism – thus denying access to non-transsexual transgender people (Califia, 1997). This results in many transgender people avoiding the psychiatric diagnosis process altogether, and not accessing medically regulated Trans Health services. Instead, they engage in self-medication through street hormone use or over-the-counter treatments, or in high-risk injection silicone use (ISU) – all without medical supervision.

Finally, the diagnosis of GID is used to psychiatrically hospitalize gender variant children where compelling patients to gender stereotyped behavior is the primary treatment goal (Scholinski, 1997; Burke, 1996).

8. ***Lack of FDA approval for Transgender Hormonal Therapy*** – (HP2010: Access to Quality Health Services, although not specifically recognized by HP2010 as medically necessary)
The Food and Drug Administration (FDA) has never approved Transgender Hormonal Therapy (THT) and considers the use of estrogen and testosterone in THT as "off-label". FDA approval is contingent upon clinical research trials establishing the safety and efficacy of THT. In the absence of FDA approval, there is a generalized lack of knowledge about transgender hormonal therapy by most physicians, who fail to recognize it as medically necessary. Clinical research is urgently needed, not only to identify the most safe and effective means of THT, but also to determine any possible adverse effects over time.

9. ***Widespread Injection Silicone Use, Especially Among Transwomen of Color*** – (no apparent HP2010 category)
Many transgender women view Injection Silicone Use (ISU) as a fast, cheap alternative to hormonal therapy that gives them their 'curves' and a passing appearance – thus affording them some measure of safety. ISU also avoids the requirements for prior psychological evaluation and preserves sexual

virility. Thus ISU also becomes an asset to transgender women who work in the sex industry, who are often asked to penetrate their male clients. ISU is widespread among transwomen of color, and there have been anecdotal reports of it in transgender men in the ball circuits of Philadelphia and New York. Studies have found ISU rates among transwomen to be 25% in Washington (Xavier et al, 2004) 30% in New York and Chicago (McGowan, 1999; Kenagy & Bostwick, 2001) and 33% in Los Angeles (Reback et al, 2001). Despite its popularity, ISU is often obtained under unsanitary conditions, with risk of viral infections including HIV and Hepatitis. It also leads to systemic illness and disfigurement, and sometimes results in death (Gender Education & Advocacy, 2003; James, 2003).

10. ***The Continuing Misclassification of Sex Reassignment Surgery as "experimental" by the Centers for Medicare and Medicaid (CMS)*** – (HP2010: Access to Quality Health Services)
The predecessor organization to CMS (Health Care Finance Administration, or HCFA) classified Sex Reassignment Surgery as "experimental" in 1973 (CMS, 2004). The classification was reportedly made by two pharmacologists, and is commonly used as one of the reasons for the exclusion of coverage of Trans Health services by health insurers (the others being it is "cosmetic" or "elective"). This misclassification persists despite these surgeries being done on a daily basis by an estimated two dozen surgeons in the U.S. alone.

11. ***Lack of Training in U.S. Medical Schools for Trans Health Service Delivery and Working with Transgender Patients*** – (HP2010: Public Health Infrastructure)
Since transsexualism and transgenderism traditionally have been viewed through the lens of a mental disorder, they are thought to be within the realm of psychiatry or psychology and thus are usually not covered in medical school curricula. Not only does this make Trans Health Services more difficult to obtain, it also produces uninformed providers who can not ask the appropriate questions about the health of transgender people, or who do so insensitively. The lack of training and transgender-specific medical information also results in providers completely unaware of the medical basis of transgender hormonal therapy and its associated health risks (Lurie, 2004); the complex and changing anatomies of transgender people; and the surgical options available to them. Consequently, they are unable to comprehensively treat their patients (Singer et al, 1997).

12. ***Medical, Mental Health and Substance Abuse Treatment Provider Insensitivity and Hostility to transgender people*** – (HP2010: Access to Quality Health Services, Mental Health and Mental Disorders, and Public Health Infrastructure)
For many transgender people, perceived provider insensitivity and hostility produces an intense fear of disclosure of transgender status, itself a significant barrier to access to care. Based upon many anecdotal reports, actual provider hostility and insensitivity has resulted in deaths through delay and even refusal to provide urgently needed medical treatment. Traumatic encounters in medical settings often will precipitate delays, not only when seeking routine screenings and exams, but also for urgent care for acute or life-threatening conditions.

13. ***Tobacco Use*** – (HP2010: Tobacco Use)
Very little, if any, data is available about transgender and transsexual men and women and their tobacco use (National Association of Lesbian Gay, Bisexual, and Transgender Community Centers, 2003). However, it is no secret that many transgender people smoke, likely as a stress reducer in enormously stressful lives. Many are lured by the depictions of feminine glamour and masculine

virility in cigarette advertising, and although there is no research, transyouth are thought to be particularly susceptible. In transgender women who take estrogen, smoking greatly increases the chances for blood clots, just as oral contraception and Hormone Replacement Therapy does in non-transgender women who smoke. Some transgender men are aware that taking testosterone increases their risk of heart disease, and that smoking simply increases that risk. As with other populations, smoking also greatly increases the chances of opportunistic infections such as PCP and Oral Thrush in HIV positive transgender people, regardless of whether they are taking HIV medications. It is also likely that progression to AIDS is even faster for transgender HIV positive smokers who are not taking HIV medications. Transgender and transsexual men and women also have reported problems in accessing smoking cessation treatment, including those located in lesbian and gay organizations (National Association of Lesbian Gay, Bisexual, and Transgender Community Centers, 2003).

End Note: Intersex people share with transgender people the medicalization of their bodies, and while the Trans Health Task Force stands as allies with Intersex people, their issues are quite different in several ways. One of the most important differences is that intersex people are frequently subjected to unwanted surgeries performed without their consent, usually in infancy, and they consider such surgeries to be genital mutilation. The Intersex Society of North America (ISNA) defines intersexuality as "a set of medical conditions that features congenital anomaly of the reproductive and sexual system." A person with an intersex condition is born with sex chromosomes, external genitalia, and/or an internal reproductive system markedly different from non-intersexed people. The Working Group wishes to make it clear, as do Intersex people, that Intersex people are in no way a subset of transgender people, as some researchers contend. However, some intersex people are transgender and some transgender people are intersex. It is our profound hope that the National Coalition for LGBT Health will take up discussion of intersex issues in the very near future.

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