HIV/AIDS-related stigma and the rate of adolescent HIV incidence in the United States:

A summary and overview of current developments in HIV education research

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As educators, their leaders, and policy makers step up to the mess that has been left in the wake of almost fifteen years of abstinence-only sexuality education, there has been a desire to return classrooms to research-supported, evidence-based programs that prioritize the students' ability to make an educated personal choice regarding their own sexual behaviors. Abstinence-only sex education has proven ineffective in deterring adolescent sexual activity, the spread of sexually transmitted infections, and the ever increasing rate of HIV incidence among American young persons. (ARI 2002) In response, the United States Congress has elected to update the archaic policies of the last two decades, replacing these with funding for evidence-based, medically accurate, and age-appropriate programs, promoting the comprehensive teaching of sexual development, physiological as well as psychological aspects of sexual activity and its risks, and a scientifically supported understanding of preventing disease transmission. However, progress has met its match in the turmoil of political gridlock. Through vindictive, partisan arguments, secretive earmarks have been added to legislation to reauthorize federal funding of the same ineffective policies that have haunted schools and the well-being of American adolescents for a generation. (AFY 2010) Even more damaging to the future health of American students, no attention has been paid in any piece of legislation to the greatest concern that sex education research has yielded in the past decade: The underlying social roots of the adolescent HIV/AIDS epidemic in the United States has been pin pointed in the common holding of stigmatizing attitudes and misconceptions regarding HIV and AIDS, and the individuals living with each of these conditions. (EducAIDS 2006)

The understanding of stigma, as a force of social interactions, has developed over the last twenty years, through an ever expanding body of research. Stigma has been described as a process,

wherein a set of attitudes of acceptable social norms and value-based beliefs, held by individuals, or more broadly among a community or society, are used to marginalize a devalued physical, behavioral, or medical attribute held by a segment of the population. (Sayce 1998, Dovidio et al, 2000) This process is marked by both enacted and perceived experiences of prejudice, developing when social, economic, and political capital is restricted from those characterized by a devalued trait. Thus, disapproval, labeling, stereotyping, rejection, exclusion, separation, status loss, and discrimination occur along side of an alignment of power that allows them to thrive. (Mutalemwa et al, 2008, Bunn et al 2007, Campbell et al, 2005, Devine et al, 1999)

While suppositions have been made throughout research literature that HIV/AIDS-related stigma may be a prevalent contributor to the rate of HIV incidence, it was not until 2002 that specific studies were initiated to explore this connection. By 2009, a multitude of qualitative studies had shown an explicit link between the dramatic rates of HIV/AIDS-related stigma and events of experienced stigma in the lives of persons living with HIV and AIDS, and the increased likelihood that an individual will contract HIV. (UNAIDS 2009) This connection has been demonstrated in research studies around the world, in Vietnam, South Africa, Brazil, China, Russia, and the United States. Community-based studies in American metropolitan regions, including Miami, New York City, Denver, and Houston, have shown that the United States is not immune to the prevalence of HIV-related stigma. Further, in these urban areas, and in other cities, as well as in state-wide and regional studies, adolescent HIV/AIDS incidence rates have steadily increased since the mid-1990s. (CDC 2007) What has become clear is that, among school-aged children in the United States, the prevalence of HIV/AIDS-related stigma in American cultural norms is the largest contributing factor to increases in HIV/AIDS diagnoses. (Close, 2008)

Among adolescents, the increased rate of HIV incidence has been shown to be linked to a decreased likelihood to seek regular HIV testing. (HHS, 2006) Adolescents do not seek HIV testing for a range of reasons, including a lack of knowledge of resources and clinics, concern for confidentiality, lack

of knowledge of the HIV status of their sexual partners, and other psychological characteristics of American adolescents. (Brown et al, 2000) Each of these reasons has been directly linked by HIV researchers to a broad fear of stigmatization by their family, friends, peers, mentors, and community. (Creek et al, 2009) It is this fear of external stigma that leads to an internal stigma, carried by individuals affected by or concerned about being affected by HIV and AIDS. (Hutchinson et al, 2006) Thus, adolescents do not seek out HIV testing, in order to know their own status or that of their sexual partners. Similarly, adolescents that are willing to seek testing initially, and are diagnosed as having HIV, are likely to never seek necessary health care interventions that could prevent the progression of the virus into the life-threatening condition, AIDS. Due to the prevalence of HIV/AIDS-related stigma among adolescents and the broader American society, young persons living with HIV or AIDS do not seek long term care and health support, and often do not adhere to anti-retroviral therapy that could prolong life and prevent HIV/AIDS-related death. (Roberts, 2005)

An extensive study into the connections between having a scientifically-supported understanding of HIV, AIDS, disease transmission, and the psychological aspects of sexuality, and the individual holding of stigmatized attitudes, including negative views of HIV, AIDS, and behaviors and individuals associated with these, was conducted in March of 2007. The study found a clear link, individually and collectively, between a lack of a scientifically-supported understanding of these diseases and the holding of stigmatized views of HIV and AIDS. (Popova, 2007) Another study found that individuals who hold particular scientific misconceptions regarding HIV, AIDS, and disease transmission are more likely to connect these misconceptions to socially stigmatized views of behaviors, individuals, and minority groups. These same individuals are also more likely to personally enact negative social views of HIV and AIDS in events of stigma, such as verbal, emotional, or even physical acts of discrimination. (Mutonyi et al, 2007) In both studies, adolescents were demonstrated to be the most vulnerable to these trends.

The following connections have been clearly demonstrated by the body of research surrounding adolescent HIV incidence and HIV/AIDS-related stigma: (1) There is a disconnect between American educational policy and sex education funding that does not meet the demonstrated needs of American adolescents; (2) Stigma occurs through a process allowed by power structures and archaic traditional values, and most deeply impacts adolescents (whose input is rarely considered in the creation of policy); (3) Culturally accepted stigma serves as a social root for the marginalization of individuals living with HIV and AIDS; (4) Stigma serves as a substantial source of adolescent disincentive to know their own HIV status and the status of their sexual partners, to protect themselves against HIV transmission, and to seek support and care from community resources and mentors; (5) A lack of quality, comprehensive sexuality education has led to the broad holding of HIV-related misconceptions and stigmatizing attitudes among American adolescents. Stigma is the root force that is promoting an American crisis of adolescent HIV incidence.

In order to respond to this crisis, stigma-reducing interventions must be designed and implemented to serve American adolescents. (UNESCO 2006) Programs seeking to reduce stigma and educate adolescents must be led by individuals viewed as meaningful sources of input, in a format and setting that will motivate adolescents to engage in a sustained dialogue about the social influences that lead to stigma and the young person's ability to fight these influences. (Attawell et al, 2005, Khumalo-Sukutukwa et al 2008, Samuels et al, 2008) Among the research that exists, discussing the elements of effective stigma intervention programs for adolescents, it has been made clear that no single strategy will suffice. It is the synergistic effect of utilizing a multitude of resources, settings, incentives, experiences, and opportunities that leads to the successful development of tolerant, accepting, nurturing communities of adolescents. (Horizons, 2001)

When HIV-related knowledge is promoted in meaningful settings with meaningful sources, attitudes of acceptance are prevalent, and HIV-related stigma subsides. As stigma falls away, adolescent

health outcomes improve drastically, including increased use of condoms, increased seeking of HIV testing and knowledge of personal HIV status, increased seeking of early care interventions for adolescents diagnosed with HIV, and increased adherence to long term care for HIV and AIDS patients, including the use of anti-retroviral therapies. (UNAIDS 2007, UNAIDS 2009)

In order to respond to the research-supported connections among HIV/AIDS-related stigma and the prevalence of HIV incidence among American adolescents, a confrontation – one that Americans may not yet be prepared to deal with – must occur. Correcting the ineffective approach to HIV and sexuality education that has long been the federal policy of the United States requires that legislators, educational leaders, and American citizens come to terms with the failures of the past implementation of abstinence-only programs, and the social roots of the policies that supported and funded these for almost two decades. These stakeholders must face the reality that the prevalence of HIV and HIV/AIDS-related stigma has been allowed to fester, and encouraged to grow by these failed policies. Until Americans are ready to face this confrontation whole-heartedly, the prevalence of HIV and AIDS among adolescents will continue to grow, and continue to take its toll on future generations.

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