

2. Preventing the Sexual

The most interesting as well as the most problematic aspect of HIV is its transmission through sexual contact. The explosive mix of ravaging disease and the most intimate of human acts has not only provided inexhaustible fuel for the epidemic but also has ignited a unique non-governmental movement to prevent its spread. Confusion has often arisen in HIV prevention when the power of sexual desire has been underestimated, the depth of human sexuality unexplored, or where prevention of the disease has been confused with preventing sexuality itself—an impossible task!

2.1 Defining the Problem

This most fundamental of questions appears to have an obvious and straightforward answer: The problem is the transmission of HIV from one person to another through sexual contact resulting in increasing numbers of people being infected according to a specific distribution in the population. Over time we have found, however, that this simple statement is far more complicated than first appears. We will examine these complications by looking at each part of the statement more carefully.

2.1.1 The Transmission of HIV

With the exception of a few persistent detractors who doubt that AIDS is caused by HIV (see Galea & Chermann 1998), it is generally accepted that the transmission of the virus is the first step in developing the immunodeficiency sickness. But how exactly is the virus transmitted?

We have known for some time that HIV is not as contagious as many other infectious diseases, including other sexually transmitted infections. In fact, the virus is relatively fragile, unable to exist for long periods of time outside the body. Also, for a transmission to occur, the mere presence of the virus in the bodily fluids of infected persons is not sufficient; the amount of virus present is crucial. Generally, the virus is most often found in large amounts in seminal and vaginal fluids, in the blood, and in a mother's milk. However, even these fluids are not always contagious to the same degree, even in the same person. During the course of an HIV infection, there are times when viral production is most active. Generally, directly following the infection and in a state of advanced illness is viral production at a peak, meaning that

the person is most contagious at those times. As techniques for measuring viral load and other indicators of viral activity have become increasingly sophisticated, we have learned that viral activity varies over the natural history of the disease, with often unpredictable fluctuations occurring. We also have learned that the virus continues to reside in the body of infected persons, even when viral loads have been reduced to levels which are undetectable under usual methods. Although a lower viral load and the corresponding low level of viral activity is associated not only with overall better health for those infected but also with a lower level of contagiousness, there is no current method of determining exactly how contagious a person is at any given moment in time. (Cf. Spandea & Puro 1999, Vittinghoff et al. 1999, Jacquez et al. 1994)

The contagious bodily fluids listed above cannot, however, spread infection through simple casual contact, but rather need more vulnerable ports of entry into the body of the new host. A conducive environment is provided by mucous membranes, such as found within the rectum and the vagina. Hence, the likelihood of transmission through sexual contact. Although the potential for the oral transmission of HIV exists (i.e., through the introduction of semen, vaginal fluids, or blood into the mouth), the likelihood of such a transmission is low (Vittinghoff et al. 1999, Keet et al. 1992, Dillon et al. 2000). By far the most common means of sexual transmission is anal and vaginal intercourse. And when engaging in intercourse, it is easier for an HIV positive man to infect his partner by ejaculating in his/her anus or vagina than it is for an HIV negative man to become infected by penetrating an HIV positive man or an HIV positive woman (Vittinghoff et al. 1999). This is so because the ejaculation of the potentially highly contagious semen onto the mucous membrane is far more conducive to transmission than the rubbing of the penis against the vaginal or anal wall which can introduce blood or vaginal fluids into the head of the penis. These basic principles allow for an endless gradation of risk in specific situations, based on the amount of fluid (blood, semen, or vaginal fluid) present, the duration of the act, the condition of the mucous membrane, etc.

As with all other contagious diseases, the transmission of HIV is also dependent on the condition of the potential new host. Extensive research has documented that the presence of active disease at the site of viral contact can enhance the likelihood of infection. In most cases this means the presence of another sexually transmitted infection (Cusini & Ghislanzoni 2001, Donders 2000).

2.1.2 Sexual Contact

The advent of AIDS has spurred an unprecedented international interest in research on sexual behavior, including the behavior of groups generally marginalized in society, such as homosexuals and sex workers. This extensive body of knowledge has produced a large array of findings. Important themes will be summarized here, followed by examples from the literature.

Sexual behavior varies by culture

Although human sexuality is related to biological need, its expression is strongly influenced by the norms and other constructs of one's culture. Cultural factors determine, for example, gender roles in sexual relationships, how homosexuality is expressed, to what degree sexuality exists outside of marriage and in what form, how and to what degree sexuality is discussed, expectations regarding sexuality, the content and management of taboos, public depictions of sexual acts, the social meaning of sexual relationships, etc. (Tuzin 1991, Hobfoll 1998, Russell et al. 2000)

Sexual behavior varies by gender

Not only biological difference but also the social construction of gender result in men and women conceptualizing and experiencing sexuality differently. Society prescribes normative ways of viewing and relating to one's own body, which generally varies widely by gender. In addition, the degree to which one is allowed to recognize and assert one's sexual needs and the form sexual expression takes are gender-based. Such differences result in women and men responding differently to various sexual situations and to information about sexuality. (Helferich 2000, Gupta 2000)

Sexual behavior reflects power differentials in society

Sexual acts are most often *not* the result of a negotiation between equal partners. Ongoing power differentials based on gender often place women in the situation of not being able to assert needs different than those of their male partners. There are also differences based on age, socioeconomic status, and social influence which can place younger, poorer, and less influential members of society at a disadvantage in sexual situations. The latter is most evident in forms of prostitution in which sex workers offer services in order to survive poverty. The most egregious assertions of power in sexual contexts are characterized by the direct use of violence or coercion in exchange for sexual favors, such as in cases of child abuse, domestic violence, and rape. (Gupta 2000, Lert 2000, Bochow 2000a)

Sexual behavior is an act of two or more individuals, not the decision of one person

As the above observations make clear, sexual behavior is the result of more than individual needs and wants, but rather something which occurs between two or more individuals. This means, as stated thus far, that the dynamics within the larger society which influence the exchange between individuals, in general (such as social class, gender, etc.) play out in a sexual dyad, as well. Also, at the psychological level, the sexual interaction is more than the sum of the wants and needs of the individuals involved, and is thus best viewed as a system of communication. Practically, this means that individuals can behave differently in a dyad—particularly in a highly emotionally-charged relationship—than they would otherwise. Thus, the quality and type of sexual relationship affects the sexual behavior which takes place. For example, there is ample evidence that sexual behavior between sex workers and their clients differs from that of romantically-involved couples which can, in turn, differ from ongoing matrimonial relationships. (Ahlemeyer 2000, Dannecker 2000)

Sexual behavior varies by age

Sexual behavior varies widely across the lifespan. Clichés which proscribe sexual activity and desire to the young are largely unfounded, although higher levels of sexual activity and higher numbers of partners are more commonly found in younger age groups. The meaning of sexuality and the types of practice in which one engages can, however, change over time, due to such factors as biological aging, accumulated experience, and living situation. (Avis 2000, Duffy 1998, von Sydow 2000)

Sexual behavior is influenced by an individual's psychological characteristics and social setting

This area has received a large amount of attention in the HIV/AIDS literature as researchers have sought to identify characteristics at the individual level which predispose people to HIV risk. An exhaustive list of the issues identified is hardly possible. This is so because of the diversity of psychological and social states which have been described, the variety of concepts and forms of operationalization employed, and the enormous diversity among the populations studied—all of which relativize the findings. Themes in the literature include: anxiety and depression, self-efficacy, self-esteem, health beliefs, alcohol and drug use, history of sexual trauma, socioeconomic

socioeconomic status, level of education, discrimination, major mental illness, and peer norms. (Hospers & Kok 1995, Santelli et al. 1999)

Sexual behavior is influenced by knowledge and skills

Studies have repeatedly documented that the level of knowledge about specific sexual practices and associated risks has an important influence on sexual behavior. However, this knowledge needs to be accompanied by the appropriate level of skill to enable people to acquire and maintain the type of behavior which they seek to attain. Although the basic information about the sexual transmission of HIV is universally valid, the necessary detail and form of knowledge can vary widely, depending on the sexual practices of the target group, their communication norms, etc. Also, the skills needed by different groups can vary widely, sex workers requiring different abilities than young homosexual men or older married women. (Hospers & Kok 1995, Erhardt & Exner 2000)

Sexual behavior is influenced by non-rational components

There has been a tendency in the literature to emphasize the rational aspects of sexual interactions, overlooking the non-rational components epitomized by the phrase “being in love.” Such components, although hardly amenable to scientific measurement, play an important role in how sexuality is understood and lived in everyday life. Highly charged sexual situations, particularly those with strong emotional content, can not only result in new and unexpected behaviors, but also in dramatic changes in how one views the world. This life-changing potential of sexuality, which has found ample expression in all forms of art and literature, is a unique and important feature of human sexual behavior. (Dannecker 2000, Mendès-Leite 1998, see also the enlightening discussion in Moatti et al. 1993 concerning the problems of defining sexual risk in terms of a narrowly defined rational response)

Sexual behavior is not a set pattern but changes over time and due to situational influences

One’s sexual repertoire is not a fixed quantity being enacted throughout one life’s in an unchanging manner, but rather a dynamic process. Even if one remains with the same partner and performs the same acts at regular intervals, the meaning of those acts in relationship to the partner evolves. Sexual behavior and its associated influences can therefore not be accurately viewed as fixed traits of an individual, but rather as an evolving expression of a person’s sexuality. Moreover, how one’s sexu-

ality is expressed can change from situation to situation and from partner to partner, even within the same period of time. For example, one may be married, have an affair, and also use the services of sex workers. In each one of those constellations it is likely that the person will express his or her sexuality differently, and that the associated behaviors will have different meanings. (Ahlemeyer 2000, Helferich 2000, Mendès-Leite 1998)

2.1.3 Distribution in the Population

Indeed, infectious diseases spread through populations, and the increasing prevalence results in a growing societal burden. But infectious diseases do not spread randomly in society; they affect certain groups more than others. HIV is no exception.

Stratification by Social Class

We have known for at least three centuries that disease and mortality are stratified by social class, meaning that people of a lower socio-economic status are generally more likely to become sick and are more likely to die younger. Researchers in the eighteenth and nineteenth centuries described the disproportionate level of sickness and death among working and lower class populations, a trend confirmed by studies conducted in the twentieth century. On a global scale, the vast majority of new cases of HIV and AIDS are found in the poorer developing world. In industrialized countries, HIV made an unusual debut as a disease of the middle class, but has since found its way down the social ladder. Epidemiological data has increasingly shown more new cases of HIV and AIDS among populations of lower socio-economic status than among their better off counterparts (WHO 1998, Luger 1998). Interestingly, this trend not only exists in industrialized countries such as the US where the differences between the richest and poorest segments of society are more pronounced (CDC 1999a,b; WHO 1998) but also in several European countries characterized by a greater equality in terms of wealth and access (Bochow 1998, 2000c; WHO 1998; Luger 1998). The reasons for the stratification of disease by social class are likely complex and numerous, their mechanisms not fully understood (see Wilkinson 1992, Kennedy et al. 1996, Kawachi et al. 1997, Duncan 1996, Brunner 1997, Krieger 1994).

Stratification by Gender

As described above, the physical means by which HIV is sexually transmitted places women at a disadvantage due to the greater ease with which infection can pass from men to women during intercourse. However, the relative social disadvantage and powerlessness mentioned earlier also explain why women can be more likely to become infected (Erhardt & Exner 2000). Although the epidemic in Germany has been largely found among men due to the dominance of homosexual transmission, the burden of disease among the heterosexual population is found among women (RKI 2001).

Stratification by Ethnicity

Although most societies are characterized by a dominant or majority culture and the presence of ethnic minorities, the composition of the various groups and their interaction at the population level vary widely. There is evidence that health indicators in general are worse for newly immigrated groups, particularly for those having left their country of origin under duress (Bundesamt für Gesundheit, Schweiz 1996, Bischoff et al. 1996, Mohammadzadeh 1996). In some countries, persistent poorer health has been documented for established minorities, such as African Americans (CDC 1999a). In Germany, data regarding ethnicity, immigration, and health are sorely lacking, resulting in no clear positive or negative trends among immigrant populations having been identified (Narimani et al. 2000). Regarding HIV/AIDS, persons from high prevalence countries (predominantly from Sub-Saharan Africa) constitute 19% of all new AIDS cases in Germany; however, these persons were most likely infected in their countries of origin (RKI 2001).

Stratification by Lack of Access to Available Services

There are groups in society who are disproportionately affected by HIV/AIDS (and other diseases) due to a lack of access to the usual preventive and curative structures of the health system. Such a lack of access may be significant for certain immigrant groups in Germany, due to cultural and linguistic difference and a lack of health insurance (Narimani et al. 2000). In any case, lack of access has definitely played a role for drug users, prostitutes, and homosexual men outside of gay structures.

An important reason for the overrepresentation of drug users among HIV and AIDS cases can be explained epidemiologically through the early entry of the virus in IV-drug using segments of the population. There was, therefore, a high prevalence of the disease before prevention and care strategies could be implemented. However,

the persistent spread of HIV and other diseases (such as Hepatitis C) among drug users is also due to the lack of access to the usual structures as a result of the social disintegration caused by addiction. Supervised using rooms (*Druckräume*), outreach-based services, and substitution programs are being implemented in Germany and elsewhere to counteract this phenomenon (Maletesta et al. 2000, Pant 2000).

Prostitution remains illegal in many countries and also continues to carry a high level of stigma. In Germany, sex work has historically operated in a gray area of the law which tolerated but did not sanction prostitution as work; the degree of persecution of prostitution varied across the country. Changes in the law taking effect in 2002 should improve the situation (see discussion in Böllinger & Temme 2001). In Germany and elsewhere it has been observed that, as a result of this dubious status, prostitutes often lack access to the usual care structures. Fear of discrimination and legal action often prohibit sex workers from coming forward for help. Also, prevention efforts have not traditionally included messages and materials geared toward the specific risks associated with sex work (Boles & Elifson 1994, Calhoun 1992, Fink 1995). In addition, the presence of many undocumented immigrants as well as trafficking in women and children add further barriers to access, given that the very existence of these groups violates the law. Finally, the situation of the clients of prostitutes continues to be largely ignored by public health in Germany and elsewhere. The few studies which have been done document important dynamics among clients which have epidemiological consequences (e.g. Kleiber et al. 1995). Although it cannot be said that prostitutes per se constitute an important segment of the HIV-infected population in Germany, there are particularly disadvantaged groups of sex workers (e.g., border prostitutes, undocumented immigrants, and male street prostitutes) which appear to carry a heightened risk due to their particularly precarious situations (e.g. Wright 2000b and Wright in press).

The largest group affected by HIV/AIDS in Germany continues to be homosexually active men. Prevention research and practice attest to the fact that men outside of gay-identified structures are the least likely to be reached by prevention messages. These include men of lower socio-economic status, men who are not gay-identified, and men who have sex with women as well as men. These men have limited access to the gay prevention infrastructure due to their weaker or non-existent connection to gay-identified institutions and norms (Bochow 2000c).

Stratification by Region

Over time, regional differences have become evident in terms of how and to what degree HIV spreads through a population. Until recent years it was common to speak of broad epidemiological patterns and to assume that these patterns are largely similar across world regions, among different countries, and within all regions of the same country. For example, the categorization of countries into Pattern I and Pattern II and the extensive literature on HIV and gay men are based on assumptions which emphasize universal characteristics while largely disregarding regional and local differences. The advent of more effective medications has drawn attention to the disparity between countries with more versus those with less resources. However, even within the industrialized world one finds a great diversity. For example, Germany and several other Central and Northern European countries have had a relatively stable epidemiological situation over the past ten years; whereas, the US has seen a dramatic shift from an epidemic largely affecting white, middle-class, gay men to one concentrating on poor women from ethnic minorities (CDC 1999b). Also, cross-national comparisons of various populations have become exceedingly difficult. For example, the US has documented a sub-epidemic among youth which is greatly changing the age-distribution of new cases in several parts of the country (CDC 1999b); whereas, there has been no evidence of such a trend in Germany, even among young homosexually-active men (RKI 2001). A great deal of variation is also apparent between regions in the same country. In Germany, there continue to be dramatic differences between rural and more heavily populated areas as well as between the eastern part of the country (*neue Bundesländer*) and the West (RKI 2001). Whether on a global or a national scale, regional variation is the norm and is the result of differences in disease prevalence, public health infrastructure, societal characteristics (e.g., income disparity, cultural attitudes, etc.), public policy, etc. As a result, it is most useful to examine national and regional trends. In regard to community-based prevention and care, reliable information about the local epidemiological situation is most important.

2.1.4 Problem Summary

Indeed, the problem is the transmission of the virus HIV from one person to another through sexual contact, resulting in increasing numbers of people being in-

fect. However, this problem finds myriad expressions, even within the same country. Important for community-based prevention is to recognize the various potential influences on the means of transmission, sexual behavior, and the stratification of HIV in the population of interest in order to describe the unique structure of the epidemic locally. Kevin R. O'Reilly and Peter Piot (1996) of the WHO and UNAIDS, respectively, provide an important statement summarizing the major themes above. This statement leads in well to the next section regarding intervention (p. S214):

Determinants of sexually transmitted diseases (STDs) and human immunodeficiency virus (HIV) have been classified into two categories: individual and populational. In fact, these two categories may be better viewed as end points of a continuum. At one end of the continuum are those factors that relate to behaviors, more or less under the control of the individual, that influence or increase risk of STDs: partner choice, frequency of partner change, and use of condoms, among others. At the other end of the continuum are those factors that lie outside the control of the individual and function more at the level of the community, society, or population. These determinants include sociodemographic, economic, and epidemiologic factors present in the community where the individual lives. Attributes of communities such as poverty, substance abuse, norms for sexual behavior, sex roles, and the prevalence of STDs and HIV infection can increase the frequency of and risk associated with individual behaviors that can facilitate or, more often, impede the ability of individuals to take preventive action.

Viewing the determinants of STD and HIV infection risk in this way is useful in that it more accurately addresses our attention to the broad range of factors that contribute to the epidemiology of STDs, including HIV infection, in a community. However, the thinking about intervention options usually is not so broad. For example, although many of the factors that contribute to the epidemiology of STDs and HIV infection lie outside the control of the individual, the bulk of interventions for prevention focus only on informing, educating, and motivating individuals to change the behavior they can control. Little if any attention is given to addressing those factors that are attributes of communities or societies.

2.2 Preventing the Sexual Transmission of HIV: Structures and Goals

2.2.1 Basic Structures and Intervention Types

A unique feature of the HIV/AIDS epidemic is the existence of a large-scale international movement—including community-based organizations, researchers, health care professionals, and others—which has shaped the discussion concerning how HIV prevention should be conducted. This movement has resulted in the creation of analogous structures and approaches throughout the world (cf. Pollack et al. 1992).

Typically, HIV prevention is organized into national or regional programs which are generally formulated and implemented by governmental or intergovernmental agencies. These programs are augmented by community-based organizations which work directly with and for groups most at-risk for infection. Kevin R. O'Reilly and Peter Piot (1996) outline the three basic types of interventions which have been created and implemented by governmental and non-governmental bodies in order to control the epidemic: *individual*, *community-level*, and *structural (enabling)*.

O'Reilly and Piot observe that the most widely applied intervention type has been those aimed at creating change at the *individual level*. Typically, such interventions are based on psychological theories which assume that the individual can and will make rational decisions about his/her health behavior. The interventions themselves consist of services such as risk counseling (providing information about transmission, risk reduction strategies, condom use etc.), voluntary HIV antibody counseling and testing, and other informational activities designed for and provided to individuals.

Community-level responses include all interventions which seek to affect at-risk groups on the collective level. This includes targeted media campaigns about risk behavior (e.g., safer sex posters for gay men), work to affect peer norms related to risk taking (e.g., sex workers' educating each other about condom use and negotiating sex with clients), as well as other risk reduction work for at-risk groups which directly addresses shared beliefs, norms, and values.

What O'Reilly and Piot call *structural* or *enabling* approaches includes all interventions seeking to change the social causes of risk which make particular groups in society more vulnerable to infection. These causes include poverty, gender ine-

quality, lack of access to services, lack of access to means of prevention (e.g., condoms), violence, etc. Such approaches are called *structural* because they seek to address social structures which limit the individual's ability to act. These approaches do not focus on risk behavior per se, but rather on social circumstances in which risk behavior takes place. By improving the social situation of target groups, such interventions lower the necessity of risk taking due to social disadvantage and need, thus *enabling* at-risk groups to make decisions which put them at less risk. Examples of interventions include public policy which provides greater access to condoms, economic strategies which provide opportunities to people from lower social classes, and campaigns which seek to influence risk-promoting cultural norms at the population level. O'Reilly and Piot report that this form of prevention is the least used of the three internationally. Although the authors argue for a diverse array of interventions from all three types as part of a comprehensive approach to HIV, they advocate specifically for a strengthening of the often neglected structural approaches. Referring to several examples of successful structural interventions, the authors write (p. S221):

What these examples suggest is that thinking about STD and HIV prevention has been perhaps too limited. Holmes¹ places many of the factors discussed above [i.e., poverty, lack of access, etc.] out of the range of the individual's control, which is true. He also implies that these factors are out of the reach of intervention or at least of interventions that can have discernible effect in a relatively short period of time. The examples above would argue that enabling approaches not only are feasible but also can be effective in a relatively short time. While these interventions are clearly not the single answer nor are they easy to implement, they may well represent an approach that has received entirely too little attention and that could be used with other approaches for STD and HIV prevention.

2.2.2 The Goals of Prevention and Their Measurement

At least implicitly, all HIV prevention strategies seek to reduce, or at least stabilize, the incidence of infection in a given population. Some programs strive to lower or stabilize the prevalence of disease, as well. Rarely, governmental bodies set specific epidemiological targets. For example the American CDC has in the current

national strategic HIV prevention plan the goal of decreasing by 50% the number of persons in the US “at high risk” for acquiring HIV and increasing the number of those infected who know their HIV status to 95% (CDC 2001b). On an international scale UNAIDS has set goals of reducing the prevalence of HIV among young people 15-24 years old by 25% and increasing access to information and education on HIV/AIDS in this age group to 90% by the year 2005 (UNAIDS 2001). Most commonly, however, the goal is a general one, namely, to lower disease incidence and prevalence as much as possible. These most basic of epidemiological markers are, however, not without problems.

The common diagnostic test for HIV is actually a test for the presence of HIV antibodies. Following an infection, it may take several weeks for a person to produce antibodies which can be identified through this method. Also, the incubation time for the disease can be several months to several years, meaning that the infected person often does not feel sick or otherwise notice that s/he has been exposed. In addition, having an HIV infection continues to carry a social stigma. These factors combined present significant challenges to producing reliable surveillance data for any given population. Even in countries such as Germany with ready access to anonymous counseling and testing services and a national surveillance program, the underreporting of cases is the norm. This is so because many infected persons are not tested or only receive a test after having developed symptoms of advanced disease. Therefore, all measures of incidence and prevalence are skillful estimates, at best. Commonly, surveillance surveys and cohort studies of higher risk populations are carried out in order to add precision to such estimates.

The use of prevalence as a marker of disease spread—or as the case may be, prevention success—is particularly problematic. Due to the above listed factors, the detection of new cases is always partial and delayed, the prevalence data reflecting infections which have taken place at some undetermined time in the past and among a certain subset of those infected who decided to be tested. Another problem has been the reduction of total cases due to AIDS-related deaths, thus subtracting from the number of those infected and potentially affecting the prevalence without any change in the number of new cases. Where more effective treatments have become available

¹ Holmes, KK (1994) Human ecology and sexually transmitted bacterial infections. *Proceedings of the National Academy of Science, USA*; 91: 2448-55.

(particularly in industrialized countries) we have seen a marked decrease in new AIDS cases which has meant extended lives for the majority of people with HIV. This fortuitous situation only further confounds the meaning of prevalence data, however: Over time, decreasing morbidity will lead to an increasing prevalence of HIV in the population (particularly in the most affected groups), even if the number of new cases were to fall. In addition, a higher prevalence could lead to a higher incidence, in that the likelihood of one's sexual partner being HIV-positive (particularly in the most-affected groups) will continue to rise. As mentioned above, however, effective treatment also generally lowers viral load and thus infectivity, which may to some degree counter the effects of rising prevalence in the sexually active population.

Both prevalence and incidence are directly related to the number of uninfected members in a population. This means, for example, that at-risk groups approaching saturation can show a steady prevalence and decreasing incidence due simply to the fact that all higher risk people in the population have already been infected. In any case, there is a likely slowdown in both incidence and prevalence over time as the higher risk segments of a population become infected while the rest of the population engages in lower risk behavior and/or has limited contact to infected persons. This results in the virus assuming a slower rate of spread outside of higher-risk groups.

Another important factor independent of trends in new infections is the migration of members in and out of a population. Depending on the nature of the migration, this could lead to positive or negative changes in incidence and/or prevalence, thus giving a false impression of how fast the disease is spreading.

The above listed problems illustrate how HIV prevalence and incidence can only be used with caution as markers of epidemiological change. Such data must always be gathered and interpreted in light of more in-depth information about the population of interest.

Until recent years, it was common in many countries to monitor several aspects of the epidemic primarily through AIDS case registries, given the extent of information gathered on each patient. This practice was always problematic, however, because of the incubation time of the disease; that is, AIDS cases reflected infections at some relatively distant and unknown point in the past. Since the dramatic improvement in treatment, AIDS case registries have lost virtually all relevance in tracking the course of the epidemic in industrialized countries, given the dramatic fall in

AIDS diagnoses. At most, the characteristics of those people with AIDS can help to identify factors (such as limited access to care) which may explain why certain people become seriously ill, even with more effective treatments being available.

The next level of prevention goals addresses indirect markers of disease spread, describing (1) behavioral phenomena associated with the sexual transmission of the disease and/or (2) the occurrence of other sexually transmitted infections which are spread in similar ways to HIV. For example, condom sales in the general population or condom use and the incidence of sexually transmitted infections in the commercial sex scene (e.g., in Thailand, Hannenberg, et al. 1994 as cited in O'Reilly and Piot 1996). Such indirect measures have been important, not only because of the limitations of epidemiological data, but also in terms of operationalizing the primary variables which prevention efforts have attempted to influence. Here, as well, one finds specific targets (e.g., CDC 2001b, UNAIDS 2001), but more commonly, general statements describing the aim of increasing protective behavior as much as possible. The usefulness of such indirect markers of changes in the epidemic is highly dependent on the relevance of the particular measures for the population of interest, which can only be judged in light of extensive information on the nature of the epidemic in the groups targeted.

Regarding behavioral outcomes, there has been an ongoing debate concerning *risk reduction* versus *risk elimination* as the goal of prevention. Risk reduction (also known as *harm reduction* or *risk management*) was first discussed as a health promotion approach for IV drug users as an alternative to abstinence-oriented programs. The argument in favor of risk reduction for drug users is that abstinence is not achievable for many, particularly in the short-term. Therefore, interventions need to be developed which seek to minimize the severity of medical and social problems associated with addiction while working over the longer term to find solutions tailored to the situation of specific individuals. Although sexual behavior and drug use are distinctly different phenomena, an analogy exists between health promotion approaches applied to each. Just as abstinence from drugs has been applied as a way to prevent the risks of drug use, the abstinence from various forms of sex (especially intercourse without a condom) has been promoted to avoid infection from HIV and other sexually transmitted infections. The latter approach—called risk elimination by its detractors—has as a goal a 100% compliance with protective behavior (such as condom

use). People who adopt but then vary from this standard are seen as “relapsing” into risk, a term also borrowed from the abstinence-based approach to drug treatment. This debate has not been resolved, either for drug users or sexually active populations, because of ideological differences between the various camps as well as fundamentally different approaches to public health theory and practice. Viewed pragmatically, the research clearly indicates that no population is capable of 100% compliance to any health-promoting norm, with sexuality entailing particularly complex behaviors and thus being even less amenable to individual control. Since the late 1980s there has been a growing consensus in Germany (and in most of Europe) that risk reduction is the most practical and realistic approach to HIV prevention for all target groups. (See a more detailed discussion in Wright 1998a,b)

2.2.3 The Structures and Goals of HIV Prevention in Germany

The structures and goals of HIV prevention in Germany are in line with the above described international trends. Unusual is the high degree of cooperation between the governmental and non-governmental sectors, the relatively large and sustained level of funding for prevention, the level of coordination between providers across the country, and the comprehensiveness of nation-wide structures for organizing the work of AIDS service organizations.

At the national level the AIDS prevention strategy is coordinated by the Federal Center for Health Education (BZgA – *Bundeszentrale für gesundheitliche Aufklärung*). The BZgA directly designs and implements educational campaigns for the general public and delegates prevention for the most affected groups to the *Deutsche AIDS-Hilfe* (DAH), the National German AIDS Organization. The DAH provides technical and professional support to the over 125 regional and local AIDS service organizations (ASOs), the *AIDS-Hilfen*, which in turn work with regional and local authorities to address specific prevention and care needs. The national strategy, broadly based on Social Learning Theory, has several primary goals and objectives (Pott 2000, p. 63):

Goals:

- Attaining a high level of information in the population about risks for infection.
- Dispelling fears based on incorrect information.

- Motivating people to protect themselves against infection when in risk situations.
- Creating a social climate which opposes the stigmatization and isolation of people with HIV and AIDS.

Objectives:

- Informing about the means of transmission, effective protective measures, the syndrome of AIDS, the course of the disease, the epidemiology of the virus, and about HIV testing.
- Motivating protective behavior which includes discussing barriers to protection, developing communication skills for difficult situations, and promoting responsibility for oneself and for others.
- Promoting solidarity for people with HIV/AIDS; for example, by exposing prejudices and stigmatization in society and by providing information on the harmlessness of causal contacts with those infected.

At the population level, the effects of the national strategy are monitored by measuring the following parameters (Pott 2000, pp. 69-70):

- Level of knowledge about infection risks
- Change in social attitudes toward people with HIV and AIDS
- Protective behavior for HIV, especially the use of condoms during sexual contact with new partners whose infection status is unknown
- Condom purchase
- Incidence of sexually transmitted infections (other than HIV)
- Incidence of HIV
- Condom use in general

The epidemiological information is collected and analyzed by the Robert Koch Institute (RKI) which administers the national surveillance program. The other information is produced as a result of representative surveys conducted at regular intervals.

The BZgA explicitly supports two major forms of intervention: mass media campaigns and approaches based on personal communication. The mass media campaigns correspond to the community-level and structural interventions described above, as they are designed to change beliefs, norms, and values of sexually active groups at the collective and population levels. Such campaigns are designed and im-

plemented in cooperation with a variety of organizations and interest groups. The second form involves the communication of information about HIV risk to individuals, thus corresponding to the individual level interventions mentioned earlier. This includes a national information hotline as well as traveling interactive exhibitions and presentations during which people can receive answers to specific questions in conversation with staff.

HIV prevention at the state and local level in Germany reflect the overall national strategy, with varying focuses, depending on the epidemiological situation and the perceived prevention needs at the regional and local levels. Important to note about HIV prevention in Germany, regardless of the level of organization, is the formulation of the goals in general terms, thus avoiding specific epidemiological targets (e.g., a 10% reduction in incidence) for certain groups or for the population as a whole.

The specific structures and goals of the non-governmental sector in Germany, the *AIDS-Hilfen*, will be detailed in the next section.

2.3 How is Community-Based HIV Prevention Conducted?

2.3.1 What Does “Community-Based” Mean?

HIV prevention developed at a time when the “new public health” was gaining momentum, meaning an increasing focus on community-based approaches, a broader definition of health in terms of well-being, and an emphasis on health promotion as opposed to disease prevention (Rosenbrock et al. 2000). In practical terms, this has meant increasing support for community-based organizations (WHO 1986):

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavors and destinies.

Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support.

The term “community” as found in the literature has been strongly influenced by its usage in the United States, based on a particular tradition of local action on the part of social minorities and other interest groups. However, as Ronald Labonte (1997) has so aptly pointed out, even in North America the term “community” is fraught with ambiguity (p. 90):

When community is defined at all, it is usually in the static vocabulary of data, creating categories based on identity (the poor community, the women’s community, a particular ethnocultural community), geography (the neighborhood, the small town, a particular housing project), or issue (the environmental community, the heart health community, the social justice community). Often, community is simply assumed to be those persons using the services of an institution and living within administratively drawn catchment boundaries (the hospital community, the school community, the university community).

*Community has all of these elements—identity, geography, issue, even institutional relations—but it is also more. Community derives from the Latin *communitas*, meaning “common or shared,” and the *ty* suffix meaning “to have the quality of.” Sharing is not some demographic datum; it is the dynamic act of people being together to share their experience and act upon transforming it. There is no “women’s community” outside of two or more women sharing their reality, empowering themselves to act more effectively upon it. As the Toronto Department of Public Health² came to define community, it “is a group of individuals with a common interest, and an identity of themselves as a group. We all belong to multiple communities at a given time. The essence of being a community is that there is something that is ‘shared.’ We cannot really say that a community exists until a group with a shared identity exists.”*

This more generic definition cited by Labonte, focusing on shared interests and a common group identity, can be applied to various cultural contexts, including Germany. Both the tradition of self-help and local action (*Selbst-Hilfe, Bürgerinitiative, Vereine*) and the closely related principle of subsidiarity (*Subsidiarität*) can be understood as expressions of community, in this sense. In recent years it has become

common to use the English word *community* in German to designate the structures and actions of particular interest groups (e.g., *schwule Community*, *türkische Community*); however, as is the case with many words borrowed from English, the use of the word *community* only obscures existing traditions in Germany. There are no *communities* in Germany in the American sense, because of a tradition which views society as a whole (not as a patchwork of minority interests) and because of the tendency for even ethnic and social minorities to seek collaboration and integration as opposed to separatism and isolation. At the practical level, self-help and subsidiarity are expressed in the way in which local initiatives are organized and financed. Concerned citizens sharing common interests and a group identity (not usually based on ethnicity or subculture, but rather on a shared ideology and vision) form organizations (*Vereine*, *Verbände*) which, in turn, seek public funding. In many cases, funding is granted if the citizens can document an unmet need or a particularly important issue. This is in accordance with the laws governing the distribution of public funding (*Zuwendungsrecht*). Thus, in a German context, *community-based* means exactly this process of self-organization being supported by public authorities.

An important aspect of the German tradition of community-based action is the implicit partnership between local initiative and public authority. This partnership reflects the broader tradition of the *Sozialstaat* as has been developed since the nineteenth century. In English-speaking countries one commonly finds social service *agencies*, that is, organizations which receive funding to act as an *agent* of the State in order to address a particular social problem. This implies not only that priorities are set by the public authority, but that the organizations are seen as part of the state apparatus and are therefore subject to control of various sorts. Receiving public funding necessarily means, therefore, a direct involvement of the public authority in an organization's structures and practices. In contrast, the German tradition is based on a *delegation of authority* to autonomous organizations which receive public funding. That is, the public authority provides funding for an organization to use its own self-defined means to address the problem. Beyond a basic level of oversight (approval of the concept, annual reports of program activity, etc.) the public authority has traditionally demanded neither information about process and outcome measures, nor has

² Toronto Department of Public Health (1994) Making choices. Toronto: Department of Public Health.

it sought to influence the structure or operations of the organization. Although in recent years there has been a growing emphasis on accountability in terms of quality management and cost containment in the social and health care sectors, the implicit belief in the appropriateness and effectiveness of local initiative which supercedes the State's exercise of control continues to be central. In terms of subsidiarity, one can argue that it is precisely the State's delegation of authority to local initiatives which saves the State from having to intervene more directly to address the problem at hand. This unique relationship between public authority and local initiative is also reflected in the independent and, at times, defiant stance which projects take toward their funding bodies (public authorities). This can include resistance of all efforts on the part of funders to gather more detailed information about the projects' work. This stance is largely unthinkable in many English-speaking countries, where the receipt of public funding automatically implies a responsibility to collaborate with the public authority in its stated mission³.

The German community-based tradition makes the use of the phrase *non-governmental organization* (NGO) problematic. Unlike in some countries, the vast majority of funding for social projects comes from public authorities, so there is always a financial dependence on the government. The use of the term *non-governmental* does make sense when differentiating between governmental structures (*Ämter, Behörden* etc.) and the voluntary sector (*Vereine, Verbände*). Regarding further innovations in the health care system the term self-help (*Selbst-Hilfe*) is, perhaps, the most relevant, as it relates directly to affected groups organizing on their own behalf. The terms *community-based* and *community-based organization* (CBO) will be used here to designate all self-help structures and local initiatives, in this sense.

2.3.2 The Structures and Goals of Community-Based Organizations

Internationally, the structures of community-based organizations (CBOs) vary widely, dependent on such factors as the availability of resources, local traditions of addressing social problems, and the history of the organization. In Germany, the

³ The current relationship between the governmental and non-governmental sectors in Germany is the result of several influences coming together over time. The Weimar Republic (the democratic regime just prior to the Nazi period) was the first to formalize state support for non-governmental organizations. In the post-war period social democratic influences as well as the social teaching of the Roman Catholic and Lutheran churches further shaped these structures. An insightful comparison of the concept of solidarity as found in the US and Germany is offered by Reinhardt (1996).

CBOs providing HIV/AIDS-related services are known as the *AIDS-Hilfen* (AHs), and are organized nationally within the *Deutsche AIDS-Hilfe* (DAH). The AHs were founded by the groups most affected by HIV/AIDS in Germany, most notably gay men, representing self-help in the most literal sense of the word. Over time, however, the AHs have undergone a process of professionalization, making self-help in the original sense only one component of the AHs structure and mission. In any case, the AHs continue to be community-based in the sense defined above; that is, they are organized and operated by people with common interests and a common ideological identity, thus reflecting the interests and identities of groups who have been most affected by the epidemic. The specific structures of the AHs can vary greatly, dependent on size, funding, local and regional priorities, etc.

An important characteristic of CBOs in the public health sector, more generally, is a broad mission statement directly reflective of the definitions and goals defined in the WHO Ottawa Charter. As an example, we find the following “vision statement” which clarifies the goals of ICASO, the International Council of AIDS Service Organizations (ICASO 2000):

- *People living with, and affected by HIV/AIDS are free from stigma and discrimination, and have access to the highest quality education, treatment, care and support.*
- *All vulnerable people and communities living with or affected by HIV/AIDS have full access to the knowledge, means and support to prevent further HIV infections.*
- *All relevant policies and programs are strategically designed with a focus on human rights.*
- *People living with, and affected by HIV/AIDS are fully involved in all aspects of prevention, treatment, care and support, and research.*

- *Communities and their organizations are mobilized and resourced to fully participate in the response to HIV/AIDS.*
- *The needs and concerns of communities and their organizations are clearly and strongly articulated.*

In Germany, this broader agenda has been formalized by the DAH under the concept *structural prevention (strukturelle Prävention)*. Based explicitly on the WHO Ottawa Charter, structural prevention rests on the premise that the “structural” barriers to health and behavior in society need to be addressed—for example, discrimination, income disparity, and cultural difference—if prevention is to have long lasting effect. In concrete terms, behavior change at the individual level is made possible through changes in the social, political, and cultural contexts which affect health and risk behavior. This implies that prevention work has, by definition, an explicit political component. The mission statement of the DAH makes this approach clear (DAH 2001; see also Etgeton 2000, DAH 1998):

Die Grundlage der Arbeit der DAH ist die „strukturelle Prävention“:

Gesundheit und gesundheitsförderndes Verhalten sind nicht nur Folge individueller Entscheidungen, sondern hängen maßgeblich von politischen, sozialen und kulturellen Rahmenbedingungen ab. Eine Prävention, die sich allein auf die Krankheit konzentriert und die Rahmenbedingungen außer Acht lässt, ist zum Scheitern verurteilt. Verhaltens- und Verhältnisprävention können nicht auseinandergerissen werden. Die Konzentration auf den Menschen und seine Lebenswirklichkeiten ist somit unerlässlich.

Im Zentrum der Prävention steht die Stärkung des Selbstbewusstseins des Einzelnen und der Subkulturen durch

- *Zusammenkommen statt Vereinzelung,*
- *Handeln lernen statt behandelt werden,*
- *Herausarbeiten der Eigenarten statt Gleichmacherei,*
- *Interessenartikulation vor Stellvertreterpolitik.*

Die DAH ist ein Interessenverband:

Vor dem Hintergrund der bestehenden gesellschaftspolitischen Strukturen muss sich dieser Interessenverband vom schwächsten Glied her definieren. Maßstab sind die sozial Diskriminierten und die von Staat und Justiz Verfolgten. Im Zentrum der Arbeit stehen daher Schwule, Drogengebraucher/innen und Frauen in bestimmten Lebenssituationen.

Der Interessenverband

- *tritt ein für Menschenwürde,*
- *kämpft gegen Diskriminierung, Ächtung und Ausgrenzung,*
- *wehrt sich gegen Radikalisierung und Entsolidarisierung dieser Gesellschaft,*
- *ist politisch und gesellschaftlich kritisch und unbequem.*

As Dennis Altman (1995) describes, it is characteristic of CBOs involved in AIDS services to go beyond interventions aimed to alter specific behavior and risk practices to include forms of outreach and community-building which have an explicit political character. The DAH and its member organizations are no exception, offering a host of practical psychosocial and medical services while working on the community and public policy level to create social change on behalf of the groups most affected by the epidemic. In reference to the three categories of intervention proposed by O'Reilly and Piot above (individual, community-level, and structural), CBOs are concerned with all three, with an explicit emphasis on the latter. It is precisely this emphasis which enables CBOs to make a unique contribution to the health of populations, going beyond the capabilities of official governmental bodies.