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## The Aids policy cycle in Western Europe: From exceptionalism to normalization

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**The Aids Policy Cycle in Western Europe**

From Exceptionalism to Normalization

by

**Rolf Rosenbrock,**

**Doris Schaeffer<sup>1</sup>, Françoise Dubois-Arber<sup>2</sup>, Martin Moers<sup>3</sup>,**

**Patrice Pinell<sup>4</sup>, Michel Setbon<sup>5</sup>**

With assistance of

**Norbert Brömme and Anne Gröger**

<sup>1</sup> Universität Bielefeld, School of Public Health, Institute of Nursing Science, Bielefeld, Germany

<sup>2</sup> Université Lausanne, Institut de Médecine Sociale et Préventive, Lausanne, Switzerland

<sup>3</sup> Fachhochschule Osnabrück, Department of Economics, Nursing Science Programme, Osnabrück, Germany

<sup>4</sup> Institut National de la Santé et de la Recherche Médicale, Unité 158: Savoirs et Pratiques dans le Champ Médical: Histoire, Sociologie, Psychanalyse, Paris, France

<sup>5</sup> Groupe d'Analyse des Politiques Publiques, Centre National de la Recherche Scientifique, Ecole Normale Supérieure, Cachan, France

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Wissenschaftszentrum Berlin für Sozialforschung  
D-10785 Berlin, Reichpietschufer 50

Tel.: 030/25491-577

## Abstract

In every Western European country the occurrence of Aids has led to exceptional innovations in prevention, patient care, health policy and questions of civil rights. This exception can be explained not only by the fact that a health catastrophe was feared, but also civilizational harm in the field of civil rights. Despite national differences, this brought about similar „exceptionalist alliances“ consisting of health professionals, social movements and those affected. With the failure of a catastrophe to arise signs of fatigue in the „exceptionalist alliance“ and increasing possibilities of medical treatment, exceptionalism in Europe is drawing to a close.

The paper elucidates specific aspects of each of the four roughly distinguishable phases in this process:

Approx. 1981 - 1986: emergence of exceptionalism. The underlying reasons for exceptionalism are investigated in this paper.

Approx. 1986 - 1991: consolidation and performance of exceptionalism. The paper investigates the exceptionalist policy model, more specifically some nationally different factors in the polity and politics that help to explain the different forms of policies.

Approx. 1991 - 1996: exceptionalism crumbling, steps toward normalization. The forces driving the process of normalization are investigated.

Since 1996: normalization, normality. The changes made in the management of HIV and Aids are elucidated using examples from the fields of health care, primary prevention and drug policies.

Aids health-policy innovations, and their risks and opportunities in the course of normalization are investigated. Three possible paths of development are identified: stabilization, generalization and retreat. The chances of utilizing innovations developed in connection with Aids for the modernization of health policy in other fields of prevention and patient care vary from country to country with the degree to which Aids exceptionalism has been institutionalized and the distance of these innovations from medical/therapeutic events. The contribution made by European countries to containing the global Aids crisis is inadequate.

Keywords: Aids, health policy and politics, primary prevention, health care, nursing, drug policies

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## **Introduction: Aids on the Path from Exceptionalism to Normality**

Compared to the mid-80s, there is a lot less excitement about Aids in Europe. The prophets of doom, who saw the entire populace threatened by HIV infections transmitted primarily via sexual intercourse and blood, have grown silent or turned to other, more spectacular fields. Despite continuously high figures for those who have contracted the disease, the epidemiological development has lost most of its drama. Its distribution, in terms of the paths of transmission and the groups impacted, is fairly stable, the main burden of the epidemic being borne by men who have sex with men as well as by drug users; the number of heterosexual infections that do not overlap with one of the main groups affected is increasing, though from a still very low level (European Center, 1998). After in part dramatic scandals in several countries (Feldman/Bayer, 1999; Setbon, 1993) problems with the safety of blood and blood products can be largely viewed as solved.

In some countries there has been a continual drop in the number of new infections, with the figures falling below the number of new outbreaks of the disease which, due to the long period of the immune system's latent struggle with the retrovirus, mirror infections incurred some ten years earlier. Prevention, research and patient care have become routine matters interrupted by new clinical advances in the field of therapy that promise to make Aids a chronic illness with long survival times (combination antiretroviral therapy; protease inhibitors, measurement of virus load, since about 1996) or – in view of its calm development – by attempts to cut back state programs for prevention and care. In Europe with all the wealthy countries reacting differently, an impending catastrophe has turned into a problem that can be managed by public health and medical care. For this reason there is talk of the “end of exceptionalism” (Bayer, 1991), of “normalization” (Schaeffer/Moers/Rosenbrock, 1992a).

Integration into evolved routines, regulations and institutions, i.e. into the “normally poor course of health policy” (Rosenbrock, 1986) is, of course, not a seamless process or one free of contradictions. That is due, above all, to the fact that in the first few years HIV infections and the outbreak of Aids attracted not only special attention in all the countries impacted but also led to a high degree of readiness to try out innovative processes as well as to institutionalize matters and disburse large amounts of money – Aids became the exception from many rules in health policy, prevention and patient care. Many people saw in these innovations not only an appropriate response to the challenge posed by HIV and Aids to health and health policy but also a pilot project for the long overdue testing of new forms of social management for other health risks prior to and after their occurrence (Rosenbrock, 1993).

Generally, normalization entails risks and opportunities (Rosenbrock, 1994a) and is a contradictory process: in the case of Aids not only for the handling of the disease but also for modernization measures in the fields of health policy (prevention and patient care) and with respect to the ‘civil society’. To understand this process and assess

these risks and opportunities it is advisable to distinguish between four phases in the way Aids is dealt with socially and politically (van den Boom, 1998):<sup>1</sup>

Phase 1 (approx. 1981 - 1986): *emergence of exceptionalism*. HIV and Aids occur. Policies have to be conceptualized, decided on, implemented and also in some cases institutionalized with a high degree of uncertainty, with sometimes considerable political tensions and within a short time frame. Aids triggers a high degree of political readiness to take innovative action and spend money.

Phase 2 (approx. 1986 - 1991): *consolidation and performance of exceptionalism*. The processes, divisions of tasks and institutions that arose as exceptionalism consolidate themselves. At the same time, it becomes increasingly clear that gays and IV drug users will remain the most affected in the medium term as well. Catastrophes in terms of incidence and prevalence do not take place. Nevertheless, Aids retains its unchallenged special status.

Phase 3 (approx. 1991 - 1996): *exceptionalism crumbling, steps toward normalization*. Persistently stable levels and patterns of new infections, calmer debate about minorities and civil rights as well as therapeutic successes indicating that Aids is turning into a chronic affair lead to the first erosion of not only its special status but also of the resources made available as a consequence. At the same time, the management of Aids is consolidated and professionalized.

Phase 4 (since 1996): *normalization, normality*. Due, for one, to successful prevention, HIV infections and Aids lead in most countries to endemic equilibriums far below the levels feared, or even decline. The alliance between health care professionals and social movements dealing with Aids reveals signs of fatigue. New antiretroviral therapies extend survival times dramatically. At the same time, market-oriented cost-containment policies gain acceptance. Some of the innovations in prevention and care achieved with exceptionalism are placed in question, while others are integrated into the normal course of politics, administration, prevention and health care.

In the following analysis of the four phases we try to uncover the main factors explaining governmental policies and public reactions towards Aids in different European countries. Of course, there is no universal or unilinear path; instead each country exhibits around a generally shared trajectory its specific configuration that should be subject of further investigations. We will concentrate on one special aspect in each of these four phases. In **phase 1 (emergence of exceptionalism)** we will examine the underlying reasons for exceptionalism. In **phase 2 (consolidation and performance of exceptionalism)**, we focus on the exceptionalist-policy model (section 2.1) and the nationally different factors in the polity and politics that help to explain the different forms of policies (section 2.2). This will be followed by a reflexion on the social and political forces driving the **process of normalization**, and

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<sup>1</sup> Although sometimes dramatic, special developments in individual countries will have to be disregarded; nor do the individual annual figures for this pragmatic classification apply precisely to every country.

thus the aspects of the political and social content of **phase 3**. The forms and perspectives of the changes made in the management of HIV and Aids because of **normality** (and thus **phase 4**) will then be elucidated using examples from the fields of policy and intervention involving patient care (4.1), primary prevention (4.2), and drug policies (4.3). This discussion will lead to distinctions between various paths of normalization as well as to clues to prognoses and the political actions required, namely in regard to Aids as well as to health policy in general (conclusion).<sup>2</sup>

### **1<sup>st</sup> phase (approx. 1981 - 1986): Reasons for Exceptionalism**

To understand the extent and content of the innovations linked to exceptionalism it is necessary to remember what reasons, despite all the national differences, led to a rather broad consensus in the industrialized countries that the threat or challenge posed by HIV/Aids could not simply be countered with the routine repertoire of health policy. This consensus was reached in general conditions in which all the industrialized countries looked at here (above all Western Europe, Australia and New Zealand) affirmed and largely implemented state responsibility at the public, general or subsidiary level for public health protection and undiscriminated access to state-of-the-art health care.

The reasons for the consensus on exceptionalism are seen mainly in the area of civil rights by some researchers. It is thus presumed that the coincidence of American homophobia with a deadly disease was a precondition for the intensity with which it was made a political issue (Ballard, 1998), while others view the influence of the gay community on the "political culture" as decisive (Altmann, 1988). In the overlapping

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<sup>2</sup> We will include material and discussions presented at the 2<sup>nd</sup> conference on "Aids in Europe" in January 1998 at UNESCO/Paris, which focused on problems of the "normalization of aids", which is occurring mainly in Western Europe. In addition to developments in these countries, illustrative findings from the USA and Australia will occasionally be included. Several important differences in the historical, cultural and institutional determinants between the European countries will be briefly touched on. The (recent) specific developments of Aids policy in the former socialist countries of Middle and Eastern Europe do not fall into the scope of this paper. In these countries Aids is still - also epidemiologically - a subordinate problem (even if some populations, e.g. IV drug users, have skyrocketing infection rates) that is dealt with 'traditional' public health strategies (i.e. repressive HIV antibody testing and border controls) (Pokrovsky, 1995, 1998). Although the European discourse on Aids was briefly stimulated in the early nineties after the wall came down, more pressing problems than Aids soon dominated the political agenda (Friedrich/Heckmann, 1995). But still there is some potential that in the course of the radical political transformations in the eastern European countries some aspects of Aids 'exceptionalism' from the Western European countries will become the standard in the emerging health care systems of the former socialist countries (Rosenbrock, 1997b). Prevention policies' first signs of progressive change are visible mainly in the Baltics, Hungary, the Czech Republic and Poland. Concepts of HIV prevention in former socialist countries have to meet the specific needs and life-styles shaped by half a century of authoritarian socialism (Herrn/Rosenbrock 1999). In contrast, other countries like Russia have not only to cope with scarce resources but also with powerful 'moral majorities' (i.e. the orthodox churches, the communist party and US-funded "pro-life" pressure groups), powerful 'traditional' Public Health institutions and a very prejudiced population impeding progressive Aids policies (Chervyakov/Kon, 1998).



area between questions of civil rights and efficient health policy, Bayer (1988) considers the main driving force to be the worry that the groups mainly affected would be 'going underground' if 'old public health' approaches were applied. Viewed more from the vantage point of social policy, Steffen (1998) sees the policy choices as following from the development of the welfare state.

A survey of national studies on the policy trend toward exceptionalism (Kirp/Bayer, 1992; Setbon, 1993; Lichtenstein, 1997; Ballard, 1998; Cattacin, 1996, 1998; Van den Boom, 1998) paints a more differentiated picture of **seven** diversely linked **reasons in the three areas of health policy, civil rights policy and social policy** that help to explain both the extent and direction of the innovations linked to exceptionalism.

a. With the extensive availability of effective antibiotics since the forties there was, in general, *widespread certainty that the age of infectious diseases had come to an end in wealthy, industrialized countries*. New infectious diseases like, for instance, the legionnaires' disease that first occurred in 1976, or the renewed increase in tuberculosis resulting from migration and growing poverty, were just as unable to shake this certainty as the constant presence of venereal diseases: the epidemics were all very limited in both geographical and social terms and proved to be manageable on the whole. Since more than three-quarters of morbidity and mortality in industrialized countries could be explained by chronic, usually degenerative diseases, scientific concern with infectious diseases greatly declined. The emergence of HIV and Aids thus had a lasting, unsettling impact on this certainty.

b. It soon became clear that *clinical medicine was powerless* in respect to the HIV retrovirus and would remain so for a long time to come. For many years its intervention was restricted to early detection of the infection (HIV antibody testing) as well as to symptomatic treatment of, mainly, opportunistic infections. The usually lethal course of the disease could not be prevented in this way. The deep belief in the feasibility of health through medicine suffered a severe setback, not only among the public but also among members of the medical and health-care professions.

c. HIV is mainly transmitted by unprotected sexual intercourse with penetration - especially during anal intercourse - and by the sharing of contaminated needles for the consumption of drugs. These *paths of transmission*, as well as continued infectiousness during the long period of latency, activated fields of significance with many taboos and archaic fears among the public. It was a matter of sex, promiscuity, homosexuality, prostitution, drugs, blood, 'unrecognized enemies/living time bombs' as well as 'premature' death. The subject of sex and drugs, at the very least, confronted large parts of society for the first time with the necessity to take a broad and public look at the forms and consequences of the social modernization processes that had taken place since the seventies (sexual permissiveness, differentiation and liberalization of narcotics). Aids suggested itself as a topic for right-wing political parties, entrepreneurs and movements that have traditionally tried to use deviant behavior and minorities as a surface on which they could project social recriminations. As a consequence, the political climate in which the reaction of health

policy had to be decided was very hot in some countries (e.g. Germany: Frankenberg, 1992; France: Steffen, 1998).

**d.** The decisions about health policy had to be made in a phase in which there were *hardly any facts or certainty* about the extent of the threat, i.e. the effectiveness of paths of transmission, the reliability and acceptance of protective strategies, etc. (van den Boom, 1998). At first, not only IV drug users but also the entire, sexually active population potentially appeared to be at serious risk. This increased the willingness to take unaccustomed measures.

**e.** The *ineffectiveness of 'old public health'* – as far as STDs are concerned – has been a common topic. Compulsory examinations, screenings, strict rules of behavior, rigid intervention in civil rights – including massive invasions of privacy – as well as quarantines, contact tracing and compulsory therapy had proved to be epidemiologically effective only in very special and politically irreproducible conditions (e.g. in armies with state-controlled prostitution) (Brandt, 1987). The greater the doubt was about the effectiveness and efficiency of conventional tools and measures for the prevention of and struggle against contagious diseases, especially sexually transmitted ones, the more the readiness to try new approaches grew. Doubts about 'old public health' tools concerned not only their effectiveness but also the ability to enforce them, above all in the context of the sexual permissiveness that had grown in the decade before Aids and the increase in importance of individual liberties in capitalist/democratic countries (Steffen, 1998).

**f.** The decision against 'old public health' was in the case of Aids easier to make because, in contrast to past epidemics, *elements of an alternative strategy were available* at least as a concept and in the form of numerous practical approaches, i.e. as concrete options for action: for a public-oriented reduction of cardiovascular-disease risks, methods and tools aimed at influencing behavior had been tried out since the 60s (Puska et al., 1985; Farquhar et al., 1990; Ballard, 1998) paving the way to new risk management strategies. It was possible to go on from their (limited) success, especially, from their concept and basic elements: community mobilization, participation of target groups in the planning and implementation of prevention, attention to people's needs and mobilization of social support, both individual and mass-media orientation to risk communication, positive behavioral incentives in the social environment, enabling and empowerment as the targets of and precondition for both individually and socially responsible risk management. In 1986, i.e. toward the end of the phase in which Aids exceptionalism arose, but independent of Aids, this basic model achieved the status of what was, at least in programmatic terms, a worldwide consensus in the form of WHO's Ottawa Charter for Health Promotion.

**g.** The choice of a strategy based on this model also suggested itself in political terms as that made it *possible to include and/or instrumentalize two movements in the public* that had arisen when Aids appeared. For one, the gay community had begun – before governments in most countries – to organize behavioral changes in their own ranks and had been calling for the social support and protection of legal and social

freedoms the gay liberation movement had fought for, sometimes militantly, since the 60s, thus providing incentives for political and social mobilization. Stimulated in part by this, a kind of cordon was formed around Aids in numerous countries by liberal/conservative, liberal and left-wing parties and/or movements that were soon joined by large sections of the health-care and psychosocial professions. This “exceptionalist alliance” (Steffen, 1998) was united not only by solidarity with the real and potential victims but also, and primarily, by a fear: the common features shared by those mainly affected on the margins of society (gays, IV drug users), or by groups considered affected (sex workers), could, through mobilization of public fear, aversion and prejudices, open the way to right-wing parties and movements for repressive measures, including civilizational harm that would go even further. Thus, there was social impetus, in the form of political pressure, for a type of intervention based on positive mobilization and activation, and there was social substance in the form of great readiness to become engaged and take action (e.g. volunteering). To this extent, and as long as this political configuration – the ‘Aids movement’ – claimed ‘political ownership’ of Aids, the disease was and will be encumbered with other reform topics of this coalition as well (health policy, health care, participation, civil rights, social policy, gender, gay policy).

In summary: the occurrence of Aids in industrialized countries has opened up a “window of opportunity” (Kingdon, 1984) for new approaches and projects in health policy of a size that is extraordinarily rare in this field of politics. The opportunities presented were utilized in nationally specific fashion to different extents and at different speeds. Some of these differences and the explanation thereof will be discussed below (section 2.2). However, we would first like to outline the features that Aids policy can or could have adopted in an optimal case. The following outline describes this model, many elements of which were realized in most of the countries, or each of which in at least one country. What is involved therefore is a synthesis of the most advanced properties of national policies that have probably not been completely implemented anywhere. This, to such an extent idealized, description can reveal which innovations – some of which point far beyond the management of Aids – are available if normalization were to unfold in the form of a simple abandonment or reversal of exceptionalism.

## **2<sup>nd</sup> phase (approx. 1986 - 1991): From exceptionalism to the model case of modern health policy**

### **2.1     *The policy model rendered possible by exceptionalism***

Apart from all the national differences (cf. below, 2.2) the synthesized ‘complete’ model of the way Aids is handled in society, politics and patient care, a **model** that

has become known as **exceptionalism**, can be summarized in **five (interdependent) complexes**:<sup>3</sup>

**a. Policy formulation procedure:** the fundamental questions of an Aids strategy (existence and magnitude of infection risks, the role of the infected, ill and affected groups, responsibility for preventive behavior, screening and HIV antibody tests on people without symptoms, the conduct of health care professionals and health insurance underwriters, access and quality of treatment and questions of labor and criminal law) were debated publicly, sometimes in very controversial fashion, and negotiated in open political systems, in part between NGOs, governments and professions. This democratic/participatory process created in an unusually short while a very high level of information and great public problem-consciousness, and can to this extent be viewed as a comparatively successful example of public risk communication, and thus of the discursive definition and assessment of a social risk (Cattacin, 1998).

**b. Actor configuration in policy formulation and implementation:** in both the process of policy formulation and the implementation of formulated policy there were – in comparison to the management of other health risks – considerable deviations in regard to both the circle of actors involved and the distribution of power and responsibility between the actors (Setbon, 1993). The otherwise strong role played by *medicine* was weakened: effective treatment of the HIV infection was not available, and mass use of the HIV antibody test, up to and including compulsory screening, was viewed as incompatible with the prevention model (cf. below in this section c.).<sup>4</sup>

The professional and institutional representatives of ‘*old public health*’ as well as the holders of repressive and police-related tools were weakened – in some countries,

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<sup>3</sup> For reasons of clarity the terminology and sequence of this description are oriented in the following to the phases and/or stages of the “public health action cycle” (National Academy, 1988; Rosenbrock, 1995a). This is by no means supposed to imply that every national Aids policy had arisen in such planned fashion as this model would suggest. To the contrary, national case studies (Kirp/Bayer, 1992) display highly different patterns and configurations of actors. In regard to prevention, for instance, matters were usually organized and action taken (assurance) before any policy had been explicitly formulated or any clear assessment made. In regard to Aids policy, the criticism of the policy action cycle elaborated for other policy fields proves to hold good: this model implicitly constricts the perspective of the political process to the perception and actions of one single, powerful actor (implicitly the respective government in most cases) (Héritier, 1993) and cannot reproduce the complex reality to be found in the development and functioning of issue communities generating governance structures with a great many state and non-state actors. The analytical benefit of the model is therefore to be found mainly in its use as “phase heuristics” (Sabatier/Jenkins-Smith, 1993).

<sup>4</sup> Their technical lack of competence did not, of course, keep many representatives of the medical profession, who were accustomed to making definitions and exercising power, from asserting ultimate competence for, for example, sexual, behavioral and media questions, for moral problems as well as the properties of condoms. In Germany this left its mark, for example, on large parts of the work that was done by the Aids Inquest Commission of Germany’s lower house of parliament (Deutscher Bundestag, 1990; Rosenbrock, 1990) and which took several years to complete. That work that was strenuous as a result but, in terms of policy formulation, successful in the long run (Frankenberg, 1992). Investigations into the reasons and consequences of the medical profession’s adherence to an ‘imperial stance’, even in conditions in which it can in fact make few contributions, are still required.

however, only after they had put up considerable resistance. '*New public health*' – and thus expertise based substantially on social-science concepts – largely occupied the positions that had been vacated as a result. This happened in most of the countries in close cooperation with *organizations of the groups mainly concerned*, above all the *gay community* (Pollak, 1991), as well as with the '*cordon sanitaire*' consisting of *civil rights movements*. The necessity to quickly put new concepts into practice required and brought about an unusually *effective transfer between research and practical application*, and, namely, in both directions (Rosenbrock, 1995b). Communication and understanding between the political, scientific and self-help community (Caplan, 1979) functioned surprisingly well under the pressure to take action. The sector-overlapping prevention approach required inclusion of the *mass media*, the *education and legal system* as well as *parts of the private business sector* (labor law, sponsoring, channels of communication).

In the field of *patient care*, hitherto underrated health professionals (nurses, psychologists, social workers) and actors in the field of *outpatient care* gained influence and importance vis-à-vis the *hospital sector*. Organizations of the groups mainly concerned, above all gays, assumed competence and tasks in the field of patient care to a hitherto unknown extent (Schaeffer/Moers/Rosenbrock, 1992a; Dodier, 1998). What was likewise new was the involvement of these organizations in questions of research, development, testing and distribution of *new medicines* (Ballard, 1998) with sometimes singular coalitions of affected persons' groups, clinical physicians and the *pharmaceutical industry*. Some of the success of these coalitions (fast track, compassionate use, policies of inclusion in drug studies, etc.) is however controversial in terms of pharmaceutical policy, above all from the viewpoint of the reliability of research results and drug safety (Wachter, 1991).

Not only the perceived magnitude of the challenge by HIV and Aids but also the extent of the innovations found in the social response exceeded the competence of the *ministers of health* in many countries: in such cases Aids policy was initiated and/or co-ordinated by *top government officials*, with Aids becoming a '*matter for the boss's attention*'. From the point of view of the state, the policy model of assurance was based largely on the delegation of tasks to what were often non-state actors, with the greatest possible self-regulated co-ordination thereof, on "*governing at a distance*" (Rose/Miller, 1992), for which governments had increasingly qualified themselves since the 70s through the incorporation of social scientists' expertise in their machinery (Cattacin, 1998), and by which governments eased their burden and increased efficiency. At the same time, policy formulation became increasingly influenced by the *international issue community* (Cattacin, 1998): ever since its emergence the main aspects of the way Aids is coped with individually and politically have been internationally negotiated and, in part, decided by worldwide conferences and a world that is rapidly growing together electronically.

c. *Policy formulation and implementation in primary prevention*: following on experience gained with community-related prevention and health promotion, and with increasingly explicit reference to WHO's Ottawa Charter (cf. above, section 1), a new

prevention concept was developed and implemented that did not try to change people's conduct by coercion, nor by simple information and appeals either, but aimed at influencing the social environment in a way that would strengthen people's motives for preventive behaviour and weaken motives in the opposite direction. That is why not only appropriate channels of communications are being expanded and used on at least three aggregate levels (nationwide umbrella messages, community-specific campaigns, personal counselling) for non-contradictory enlightenment and educational messages. In addition, attention is also being given to optimization of the preconditions for communication with and within the target groups and/or communities. That not only implies incompatibility between public discrimination (including police persecution) and prevention of infection within the target groups based on a credible partnership but also leads logically to the consequence that the target groups' life styles, milieus and structures (e.g. meeting places of all kinds) must be viewed and, as the case may be, supported as communication possibilities (community building, community organizing). Factors that weaken the effectiveness of prevention efforts (e.g. inequities in gender relations and socio-economic status; see Luger, 1998) are taken into account in the conception of prevention and turned into issues as factors requiring modification. The approach, starting points and contents of prevention (Rosenbrock, 1995c) are basically linked to the capabilities and needs of the target groups, and are thus primarily related to resources (to be augmented) and not to deficits (to be eliminated). Together with the organization of the most unhindered access possible to the technical means of prevention (condoms, lubricants, sterile syringes) group-related and self-organized incentives are thus created and stabilized with the aim of establishing and strengthening social norms for risk-avoidance (safer sex, safe use) and health-conducive behavior based on solidarity. The responsibility for preventive behavior is assigned equally to the infected and non-infected. That also includes the (moral) obligation to inform one's partner before and after exposure to potential risks. The realization of this approach to the prevention of a mainly sexually transmitted disease forms a transition from "despotic", individualized direct control to "infrastructural", regular, continuing and indirect controls (M. Mann, 1986), from the "control and containment" approach to that of "inclusion and cooperation" (Bayer, 1989), from an "individual search strategy" to a "publicly learning strategy" (Rosenbrock, 1987a). Since it is very difficult to intervene directly in the actual zones of risky behavior (sex, drug use) as, in part, criminalized areas involving taboos and a sense of shame, other institutions, above all the education system (e.g. sex and drug education) and legal policy (e.g. criminal law, protection against discrimination as well as social and labor law), are also pulled into prevention policies. In drug policy, principles of exclusion and prosecution collide with the requirements of Aids prevention. Policy changes are related to the social and legal definition of IV drug use (deviant behavior, disease, crime) and IV drug users, the abstinence dogma as well as the availability of sterile needles and the establishment of methadone and/or heroin programs (cf. below, section 4.3). The inclusion of sex workers is a matter of decriminalization and social rights. Prevention thus becomes a cross-sectional project overlapping various sectors.

d. *Policy formulation and implementation in health care*: the professional health-care system initially displayed defensive reactions, up to and including denial of access and treatment to Aids patients. There were, for the most part, three reasons for this: HIV and Aids could not be treated, or only with little success, treatment was linked to risks of infection (which, though very slight, were avoidable by maintaining hygiene), and the patients came from marginal social groups whose life styles and survival strategies (above all in the case of IV drug users) partially collided with the routines and control needs of the medical and health-care professions. These factors, as well as the quickly arising need for humane and solidarity-based attendance to Aids patients in phases of severe disease and when they were dying, addressed the strong motives of autonomy and participation throughout the “exceptionalist alliance” (Steffen, 1998) and also directed the movement's attention and energy to the shaping of patient care early on. Structural changes in patient care – that were for chronic diseases already in process but lacked wider recognition – were in this situation finally rendered possible with the initially strong support from health-care professionals (physicians, nurses, psychologists, social workers). These advances in the field of care aimed primarily at improving life quality and making patient-orientation the central guiding maxim.

The focal point was therefore to keep hospital stays as short as possible, to give priority to making care available on an outpatient basis, to create the necessary infrastructural preconditions there and also to facilitate the improvements required in the cooperation and coordination of health care professionals and institutions. Moreover, great weight was placed on the inclusion of NGOs, community-based services and clinics as well as patients' participation so as to thus permit individual choices in regard to the different paths the patients and their care could take. As a result, an important step was taken from service orientation in health care to need orientation – a constitutive element of ‘new public health’. Corresponding adjustments were made to patient care, with considerable, nationally specific differences. The variance ranged from expansion of conventional structures in countries with already modernized patient-care structures (e.g. Switzerland: Kocher, 1993; The Netherlands: van den Boom, 1998) to enclave-like bulges in normal care (e.g. Austria: Dür/Haas, 1992) up to and including the establishment of specialized facilities (e.g. in Germany special, community-based nursing services as well as medical practices specializing in people with HIV and Aids, medical practices for the controlled administration of methadone for substitution purposes [Moers/Schaeffer, 1992a], Aids wards in hospitals with special co-ordination of the transition to and from outpatient care [Schaeffer/Moers/Rosenbrock, 1992; Moers/Schaeffer, 1992b; Schaeffer, 1995a, 1995b; Fassin, 1996; Souteyrand, 1997; Bungener, 1998]).

In the field of patient care the question of whether specialized service and care organizations (categorical services) should be created and/or fostered for certain diseases or groups of patients was argued about from three different points of view: quality of care for patients with specific needs, non-discrimination, and prevention of infections of health care workers (van den Boom, 1998). As an outcome of this multi-

level bargaining the primacy of general services remained unchallenged, but numerous specialized services and a variety of combinations came into being.

The often bitterly conducted debate (e.g. Rogers/Osborn, 1991) about assessment and the risks of infection existing there (necessity and sense of testing patients and health care professionals) was officially “ended” with the integration of patients in the general care structures and with efforts to follow the rules of hygiene, and unofficially with frequent pressure on patients to get tested, or even with secret tests.

In no country were innovations in the health-care system so intensively evaluated as the performance and outcome of prevention. That made it easier to take back reforms in later phases (cf. below, section 4.1).

*e. Screening Policy and risk assessment:* the HIV antibody test in 1984 provided a technical tool for determination of a person’s serostatus. The purposes, extent and conditions of this tool’s use formed a central ‘contested area’ in the medical and health-policy negotiation of Aids policy. The ‘exceptionalism’ concerning Aids screening policy is the change in the test’s objectives (Setbon, 1993). Weighty reasons spoke against broad or even compulsory use thereof in primary prevention (Rosenbrock, 1991, 1994b). This led to both political and scientific disputes which, over and beyond the area of Aids, placed large parts of the secondary preventive approach in question (early detection for early beginning of individual intervention and/or behavior modification and/or therapy) (Holland/Stewart, 1990; Abholz, 1994; Miller/Lipman, 1996). From a technical point of view the test had the disadvantage of detecting infections only after antibodies had formed, i.e. some 12 weeks after contact was made with the virus (diagnostic window). In addition, deficits in sensitivity (risk of false negative findings) and specificity (risk of false positive findings) spoke against mass screenings and in favor of carefully limiting its use mainly to the safeguarding of blood donations and blood products as well as to differential diagnostics in the case of symptomatic patients. In social terms, the basic decisions were not the only thing to speak out against coercion and for a prevention strategy based on community-related learning, against mass screenings and for testing restraint, up to and including test discouragement (v. Wijngaarden, 1992; van den Boom, 1998). There was also the fact that the simultaneous transmission of ‘safer sex in any encounter outside strict monogamy’ and ‘test’ messages violates the precepts of simplicity and freedom from contradiction in prevention. This position was supported by social scientists’ findings that were unable to substantiate relevant improvements in preventive behavior attributable to the test (as individual risk assessment) (Cleary et al., 1988; Michel, 1988; Higgins et al., 1991; Zenilman et al., 1992; Gill et al., 1998). A sensible and also publicly recommendable use of the test was foreseen for the future, namely in the event that medical treatment became available and its effectiveness and efficiency were to rise with the beginning of therapy as early as the symptom-free phase (c.f. Rosenbrock, 1986).

All in all, the prevention model chosen and the political and scientific dispute about the HIV antibody led to the development and application of a whole number of



methodically innovative approaches to epidemiological risk assessment, surveillance and evaluation (Dubois-Arber et al., 1988, 1997a; de Vroome et al., 1990; Mertens et al., 1994).

If, as done in this section, the elements with the greatest development (the partial best cases, so to speak) are put together to form an 'ideal' overall picture for each respective national Aids policy, it can be seen that in the handling of HIV and Aids it was possible to realize numerous innovations at every stage of the public health action cycle – innovations that in earlier years could not be pushed through in many countries, often for decades, against the backwardness of public health (Thiaudiere, 1998) or against "reform blockades in the health system" (Rosewitz/Webber, 1990), even when there was adequate evidence of the advantages entailed thereby in respect to access, equity, quality of care and cost-effectiveness. The further fate of this model and its role in the process of normalization is therefore of health-policy and health-science significance far beyond the Aids community.

## 2.2 *Differences in baseline and performance of the exceptionalist model*

The health policy models actually implemented in capitalist European countries for the management of HIV and Aids due to exceptionalism may have been astoundingly similar in terms of their fundamental features (Kirp/Bayer, 1992) – compared with the variance to be found in other fields of health policy – but there were, and still are, considerable differences in these fundamental features. These differences are to be found in the following in respect to all five fields of innovation outlined (cf. above, 2.1): in southern European countries, in particular, the process of policy formulation began with a great delay. The formulated policy likewise differed, for instance, in respect to the role played by the HIV antibody test in primary prevention, e.g. between the Swedish position, with its strong advocacy of testing (Henriksson/Ytterberg, 1992; Setbon, 1993), the German position in the middle (every person at risk should find consultation – and then be tested if necessary) (Frankenberg, 1992) and the Dutch policy of official and public discouragement of the test (v. Wijngaarden, 1992). The exceptionalist alliance's distrust of possible abuses of the HIV antibody test also extended to the question of whether 'unlinked anonymous testing' was permissible as a tool for assessment and evaluation. In The Netherlands it was not put to use due to a test-averse policy that placed its hopes, on the whole, on 'new public health' (Kirp/Bayer, 1992), while the use of this tool before the background of a long and controversial debate about privacy and public health in Great Britain took two years to approve (Steffen, 1998). In Germany 'anonymous testing' was first used as a symbolic substitute strategy in the state of Bavaria by the 'control and containment' faction, the health-policy losers (Beckstein, 1992), and led to "few benefits and high costs" (Fechter, 1992).

Frank campaigns conducted without discrimination of extramarital sex, particularly condom advertisements, met with long delaying tactics in southern European countries shaped by the catholic church (Cattacin, 1996). In liberal and/or protestant

countries like Switzerland (Kocher, 1993), The Netherlands (van den Boom, 1998), Australia (Ballard, 1998) and New Zealand (Lichtenstein, 1997) there was, on the other hand, no or only brief resistance. Germany and Austria hold a position in the middle (Frankenberg, 1992; Cattacin, 1996).

The involvement of NGOs and representatives of the gay movement in the Aids policy configuration, and thus in its negotiations and decisions, differed considerably, e.g. between what tended to be a more closed political system in Great Britain (Steffen, 1998) and the system in The Netherlands, with an evolved tradition that included civil society organizations (van den Boom, 1998).

If the peculiarities of the topic, political process and arena (cf. above, section 1) are taken into account, it is no surprise that policy differences did not fall in line with the three basic types of liberal/market, social democratic/state or conservative/social insurance European social and health policy (Esping/Anderson, 1990): the variance between countries with a largely social-democratic/state-run health system is much greater between each other (e.g. in respect to the role of the HIV antibody test between Sweden: Henriksson/Ytterberg, 1992; Denmark: Albæk, 1992; UK: Steffen, 1998) than, for instance, with countries with a central-European/conservative type of social insurance. The countries with Aids policies that come closest to the ideal model outlined above include not only Switzerland, with its strong market-economy regulation of health policy, but also The Netherlands, with a social-insurance model (Kocher, 1993; van den Boom, 1998). Aids did not have a career as an issue as part of the health-policy arena, nor were Aids policies decided solely on the basis of the logic and the rules of this arena.

Instead, in the way the epidemic was turned into an issue and managed it is possible to distinguish between influences from three arenas (Lowi, 1964; Rosenbrock, 1985) which, as a configuration consisting of institutions, professions and other actors as well as norms, mentalities, values and procedures (i.e. "cultures") (Bütschi/Cattacin, 1994; Cattacin, 1998), make up the polity (Heidenheimer, 1986; Ruetten, 1995) that formed around Aids: in this respect not only factors from the health policy arena but also from overlapping political/state and political/social polities are of importance.

In Europe the tasks of the health policy arena have undergone a secular process in which they were largely reduced to the regulation and financing of medical intervention involving individuals (McKeown, 1979; Rosenbrock, 1998a). Within this scope it was necessary to clarify three questions in connection with Aids:

(1) Should the care of Aids patients and people infected with HIV be financed, as with all other diseases, by the state, social insurance or profit-oriented health insurance companies? After initial uncertainty (in Germany: Rosenbrock, 1986), and with enduring imperfections in the case of for-profit insurance companies (Steffen, 1998; van den Boom, 1998), the question was clearly decided in favor of inclusion.

(2) Should physicians routinely and, in certain circumstances, test patients and people seeking advice about HIV without their informed consent? After initial

controversies and changes in position, e.g. in Great Britain (Steffen, 1998) and Germany (Frankenberg, 1992), the majority and/or the representatives of the medical profession did no longer favor the 'individual search strategy' (cf. 2.1 c.). The reason for this reticence is probably due less to questions involving the exercise of power conferred (by the state) on the medical profession (Freidson, 1970) or the different shape of power relationships between the state and the profession (Daheim, 1992) than to the fact that any other decision would have made physicians key figures in the conflict between the defenders of 'old public health' and the "exceptionalist alliance". With this result, and for reasons to be found not only in the health policy arena, the profession abandoned a routine that sees 'an end in itself' in early detection examinations – often without any attention being given to desirable and undesirable effects (Holland/Stewart, 1990). Physicians who nevertheless, and often, tested without informed consent were threatened with criminal-law consequences in some countries (Frankenberg, 1992).

(3) Finally, questions of access to and the structure of patient care had to be decided in the health policy arena. Health care policies differ nationally, depending on the extent to which (a) 'new public health' had already made its way into the health care system, it only being necessary, as a consequence, to make adjustments (The Netherlands, Switzerland, Great Britain), (b) the extent to which health-care groups and institutions capable of acting were prepared to take up Aids as a test case and pilot project for modernizing reforms (e.g. Germany, France) and (c) the extent to which the general, social secularization process had advanced: health care policy proved to be much more 'hesitant' in southern Europe and, likewise, in Austria.

The policy answer to Aids, above all the prevention model, was largely removed from the influence exerted on state policy formulation by individual-oriented, in the last analysis, clinical expertise. That also applies in cases where – mainly due to the gay movement's organizational weakness – the stimulus for policy formulation came from the medical profession (e.g. medical university professors in Italy, cf. Steffen, 1998). The task of formulating prevention policy was thus shifted to a widely state-controlled, public-health machinery that varies greatly from country to country in terms of its size, weight, reputation and approach, a machinery that in many countries previously to Aids had only been marginally perceived as part of the health policy arena. These institutions' proposals which eventually had to be decided by governments were usually made in direct negotiations with representatives of the exceptionalist alliance – the outcome not least depending on the strength of 'new' versus 'old public health' representatives inside the institutions. The relative strength of the 'new public health' approach varies from country to country, and primarily in terms of the extent to which approaches to modern health promotion had already been tried out prior to Aids in the respective country and had been recognized by government representatives (strong in the USA: Kirp/Bayer, 1992; New Zealand: Lichtenstein, 1997; Australia: Ballard, 1998; Great Britain to limited extent: Street/Weale, 1992; Gill et al., 1998; weak in Germany and Austria: Frankenberg,

1992; Cattacin, 1996; almost non-existent in southern European countries: Cattacin, 1998). The possibilities of forming exceptionalist alliances varied accordingly.

The dimension of political participation by and inclusion of voluntary organization, mainly those of the gay community, but also those of hemophiliacs, sex workers and IV drug users, may be unfolding in the health policy arena, but it depends on the state of the political/state culture. Before the background of highly different traditions and reasons for social participation The Netherlands (van den Boom, 1998), Switzerland (Kocher, 1993) and Germany (Frankenberg, 1992; Rosenbrock, 1994a; Cattacin, 1998; Steffen, 1998) arrived at structurally similar results that did, of course, differ in terms of the degree of state dependence of the NGOs involved, and thus in respect to their ability to handle conflicts. That the inclusion, for instance, of the gay movement was due more to the properties of the polity than to the development of political pressure can be seen in the German example: even though the gay movement was organizationally extremely weak when Aids arose after the movement's heyday in the 70s, the German Aids Help (DAH) founded by just a few activists was recognized at once as a political partner because Germany's participative culture required such an actor (Rosenbrock, 1998b). In Great Britain, on the other hand, policy formulation and decision-making were more likely to take place in a closed space between an initiating public health system (Steffen, 1998) and the government (Street/Weale, 1992). In France, the struggle against Aids was mainly initiated by NGOs and only later recognized and supported by public health authorities (Pollak, 1992; de Busscher/Pinell, 1996). In southern European countries with a less marked culture of participation, organizations of affected groups, in contrast, found hardly any access to the arena of state decisions. This led, among others, to smaller size and less spin-off of Aids-related institutions (Cattacin, 1998).

The extent to which the political/state culture of participation and cooperation opens up to marginal groups like homosexuals, IV drug users, sex workers and as a consequence of spin-off (Thiaudiere, 1998) to other groups like, for instance migrants as well (Haour-Knipe, 1994; Wellandt/Bademill-Wiecha/Geiger, 1996), depends for its part on the political/social culture. It determines - mainly as a product of religious and civil-society traditions - the climate toward factors that account for Aids' field of significance: sex, homosexuality, promiscuity, drugs, minorities and generally deviant behavior. In general, this was easier to do in the northern protestant countries of Europe than in the southern catholic nations (van den Boom, 1998; Cattacin, 1998). That the political/social culture doesn't always function in line with the logic of the health policy arena of the same country is illustrated by the Swedish example: although the health policy arena was obliged to the 'old public health' model, the political/social culture at the same time demanded inclusion of the gay community (but not IV drug users, who are treated as 'sick' in the logic of the 'old public health' model). This combination, for one, led to that well-known compromise in Swedish Aids policy between 'old' and 'new public health' which, with its combination of community mobilizing, strong encouragement to undergo tests, compulsory partner notification and compulsory isolation as the severest

intervention (Danziger, 1988), is actually considered to be impossible and probably would indeed be impossible in other countries with historically greater burdens on the trust between citizens and the state (Fox/Day/Klein, 1989).

This short look at national polities in whose institutions, configurations of actors, norms, selectivities and mentalities the respective Aids policy had to be decided and implemented shows that even with sometimes far-reaching innovations, as in the case of political Aids management, "path dependency" (Carmines/Stimson, 1989) forces always remain in effect as well. Above all, however, it becomes clear that the length of the leap to an exceptionalist model differed in different countries, that the exceptionalist model (first designated as such from the US perspective [Bayer, 1991]) was sometimes closer to and sometimes further from the social and political way of handling health problems, civil rights and minorities that had evolved anyway. For The Netherlands (van den Boom, 1998) the model is hardly exceptional but more an appropriate and flexible reaction based not only on the health-system structures that had evolved there anyway but also on its culture as regards the handling of new social challenges like sex, drugs and minorities. Similar remarks apply to Switzerland (Kocher, 1993). In Australia (Ballard, 1998) (and in part in Scandinavian countries as well) the adoption of the health promotion approach for the purpose of prevention had already been rehearsed when Aids arrived. In Great Britain, the debate about civil rights/privacy in respect to efficient prevention of sexually communicable diseases had already reached a high level, the results of these debates having been written into the routines of the state and the public-health machinery (Steffen, 1998). In Germany, on the other hand, this debate was conducted briefly and acrimoniously only after Aids had become an issue (Rosenbrock/Salmen, 1990; Frankenberg, 1992). The picture in southern Europe, especially in Italy, Spain and Portugal, was a different one: a socially dominant, in the last analysis, Roman Catholic tradition of rejecting any sexuality not directed at procreation (i.e. not turning extramarital sex into an issue, at the very least) hindered the political perception and handling of Aids. The distance from the starting point dictated by the polity and/or political culture to an Aids health policy based on the logic of exceptionalism was overcome in these countries only after considerable delays and with considerable shortcomings in its implementation.

The reasons for national deviations from the exceptionalist model of Aids policy are not to be found in the polity-defined distance of this model from customary risk management but in the interaction and debates between the political actors and parties, the political process in a narrower sense, i.e. in the politics (Setbon, 1991). Its rules and limits may be influenced by the polity and/or political culture, but they are by no means determined thereby (Heidenheimer, 1986). It is, for example, plausible that the success of the exceptionalist model in open and victorious confrontation with right-wing parties and movements, as in Germany (Frankenberg, 1992) and France (Steffen, 1988; Thiaudiere, 1998), is conducive to the implementation of solidarity, protection from discrimination, participation and the institutionalization thereof. Such confrontation led in France to the development of NGOs not primarily based on

the gay community but on an alliance of homosexuals with different social and professional groups (mainly composed of heterosexual women) (de Busscher/Pinell, 1996; Pinell/de Busscher, 1996). That naturally applies less to countries in which these values were already relatively secure and institutionalized by history and polity. Militancy as well as a high organizational state of NGOs not only in the field of health and minorities but also, in particular, in the gay movement will surely also tend to be useful factors in pushing through as much as possible of the exceptionalist model in a given polity. That can be seen, for instance, in the nationally very different power, role, and influence of ACT UP in the first few years of the epidemic (Steffen, 1998). It is surely also significant whether the respective central government first assumes a leading role due to an acute crisis (e.g. contaminated blood in health care, France: Steffen, 1998; Australia: Ballard, 1992) or whether this takes place within the framework of routine governmental practices (e.g. the UK, Street/Weale, 1992; Steffen, 1998). In the first case, ad-hoc solutions within the scope of short-term crisis management are more probable, these solutions advancing the exceptionalist model only in fortunate circumstances. In the second case, integrated and thoroughly planned management have greater chances.

It can be seen that the degree to which the exceptionalist model of Aids policy was pushed through in various countries and in different ratios of mixtures depends, for one, on the structures and methods of solving health-policy problems existing at the beginning of the epidemic, on the political/state culture and polity, and, for another, on the concrete course taken by the clashes and coalitions in the definition of policy, i.e. on the politics.

The special political case of Aids has led in the end to differently stable institutionalizations (Cattacin, 1998) and to changes in the definitions of social problems (Thiaudiere, 1998). These innovations form not only the pattern of the respective national Aids management but also change – in a kind of feedback – the polity as a whole. Both factors – the response to the pattern adopted for coping with the Aids challenge (perception of the problem, assignment of tasks to actors and institutions) and the changes brought about by Aids in the social perception of risks, disease, sexuality, drug abuse and deviant behavior – form the initial social situation with which the process of the normalization of Aids meets.

### **3<sup>rd</sup> phase (approx. 1991 – 1996): The forces driving normalization**

Normalization designates quite generally a process in which a phenomenon that was previously considered as extraordinary (unknown, large, small, good, bad, threatening, enriching) loses this status and returns to the world of the familiar and customary in terms of perception and action. Public attention declines or is restricted to the – often ever smaller – issue community. At the end of the process deviation from the general rule, i.e. exceptionalism, is neutralized.

Aids, too, was caught up by these dynamics. After just about a decade exceptionalism began to erode, and in every western industrialized country, starting in the USA, a country that always played an avant-garde role in the Aids debate, a process of normalization began, and is still going on, that struck individual nations at different points in time. For the most part it is distinguished by the fact that Aids advanced from what was socially a barely controllable risk to a manageable disease (Benjamin, 1989), to just one health and social problem among many, while undergoing at the same time a process of depoliticization.

The forces driving normalization are of different natures, with unspecific and Aids-specific causes:

### ***3.1 Unspecific causes of normalization***

**a.** Basically, societies display a remarkably great potential to come to terms with new risks in the short or long run and, in this sense, to normalize them. To start the process and keep it running it is not necessary for the risk phenomenon initially perceived as extraordinary to have diminished or changed, or to have lost its potential to pose a threat because it is being dealt with. People grow accustomed to phenomena of the natural, technical, economic, social and political environment, phenomena initially perceived as exceptional before being turned into issues, simply because at some time or another these phenomena are treated less and less as issues and are then defined by society as 'normal' by virtue of mute agreement and definition (Cattacin, 1998; Thiaudiere, 1998). The continuously growing ozone hole, the widening gap between rich and poor or dying forests are just a few examples. The "issue attention cycle" (Downs, 1972) describes the forms of and the course taken by this sometimes frighteningly capacious ability of individuals, groups and societies to first be alarmed about catastrophes and then come to terms with them by neglecting them. According thereto, a period of high social and public attention accompanied by bitter debates is inevitably followed by a phase of fatigue and declining interest in the issue. That shows and explains in part the decline in political attention, the dwindling willingness of the state to provide funds, the scantier media coverage, less willingness to make donations or volunteer.

**b.** At the same time, other topics start to elbow their way to the fore and overshadow the explosiveness of the problem once viewed as an extraordinary one. The fear of Aids as an infectious disease was, for instance, overshadowed or relativized by the repeated emergence of (limited) Ebola epidemics, the (controversial) flare-up of cholera in India, BSE or the chicken virus in Hong Kong, etc., not to forget infectious epidemics (once again taken note of as a consequence of Aids) like TB, malaria, etc. that are continuing almost unchecked in poor countries. The Aids phenomenon, a social health problem, has lost some of its paradigmatic 'glamour' as a result of new research that is increasingly postulating and/or identifying medication-susceptible microorganisms as the agents causing diseases like arteriosclerosis, heart attacks, strokes as well as abdominal and duodenal ulcers, diseases long thought to have

been caused by psychosocial factors.<sup>5</sup> The renewed and increased pressure for cost containment in the field of health care (WHO, 1996), which arose in nearly every industrialized nation with a certain amount of delay and which initiated far-reaching restructuring of their health-care systems, was decisive for the normalization of Aids as a health-policy problem. The pressures to save that were allegedly generated by a global market and which were made an issue of in this respect led to an upturn in neoliberal concepts, including those involving health policy. The emphasis on the market and competition as a control medium inherent in this approach generally lead to declining sensitivity to problems of socially related inequity (Evans, 1997; Rosenbrock, 1998c). People with a lower socio-economic status, marginal social groups as well as people with severe and chronic illnesses, to which Aids patients successively advanced, can hardly expect any special preferential treatment from this model. Finally, the overall political situation also changed in lasting fashion. In this context it is necessary to cite unification of what were formerly two separate states in the case of Germany, but also the fall of the iron curtain for Europe as a whole, which resulted in other problems and necessities finding themselves on the political agenda.

These factors not only absorbed large parts of public and political attention but also led to the consequence that previously open 'policy windows' were closed, and the political and financial latitude for the adjustment expenditures and innovations required to cope with the Aids risk became narrower.

c. At the level of the actors working in direct contact with the risk in the fields of prevention and patient care, the waning and withdrawal of social attention have severe consequences: normalization entails sharp setbacks and crises in motivation in this sphere. On the one hand, that is due to the fact that in the long run it is very hard for people to maintain the extremely high commitment and willingness to act of the kind found in times of exceptionalism, and they also have to rely on social gratification (Ullrich, 1987; Aust, 1996). When public attention declines, the gratification potential disappears and thus one of the central wellsprings of regeneration for the maintenance of high commitment dries up (Schaeffer/Moers/Rosenbrock, 1992a). This is accompanied by another factor: at the actors' level exceptionalism is usually linked to the rise of a pioneering spirit and to the fact that their actions are accorded the charisma of the special and extraordinary. But charisma and the pioneering spirit have to be constantly refreshed if they are to avoid becoming mundane, worn-out matters – thus requiring, in fact, further, new exceptionality. When they subside, the potential from which pioneering spirit can be reborn is exhausted, and a process begins in which charisma fades. The exceptionalist alliance consequently loses a central reference point as well, as a result of which a further decline in public attention is fostered. Because of these dynamics, which in sum aggravate the decline, the actors are confronted with the problem of

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<sup>5</sup> The example of the USA shows that – especially in socially conservative phases – there is a great tendency to deprive health problems of their social content whenever possible and to reduce them to microorganisms that can be fought against in individuals with the help of medicine (Kühn, 1993).



how to grasp the change in demands entailed by the transition to normalization and how to cope with the redefinition and readjustment processes required for that purpose.

**d.** Exceptionalism always requires extraordinary solutions and innovative action. The ability to follow up and integrate is called for, however, with the transition to normalization. Because of this change in demands, for which the potential is, however, much smaller at a subjective level – as indicated above –, the transition to normalization is in many cases tantamount to a crossroad: many founding actors leave the field or push their way into other fields or positions. The actors streaming into their positions have other priorities and are less sensitive to the guiding notions and achievements – that often pointed far beyond Aids – attained in the early years. The transition from exceptionalism to normalization is, as a consequence, usually linked to changes in the actor configuration and also to the fact that new – or to put it more correctly – other concepts for coping with the risk as well as other subjective configurations of interests gain the upper hand: they are distinguished less by an altruistic search for ways to master the risk than by a search for a subjective image, and are thus inspired less by utopian considerations than by realistic ones, which in factual terms usually means utilitarian (Schaeffer/Moers/Rosenbrock, 1992a). That is why these transitions often have the character of a fracture at the micro-level; they may be able to ensure a link with new challenges, but they are also linked to discontinuities in respect to the priorities and maxims once pursued.

**e.** In western industrialized societies the management of risks, including the Aids risk, is often given a nudge by social movements. It consequently bears features of a social movement and is also subject to the latter's thematic twists and turns (Rucht, 1994). They are distinguished by the fact that topics exhaust themselves and can no longer trigger stimuli and, after a period of commitment, the actors in the exceptionalist alliance turn to other topics, that in social terms have not lost their status as issues or have turned into new issues. It is very much in this sense that in nearly every European country Aids led to a strengthening of the self-help movement. In many countries the NGOs were the first and decisive actors to call for and realize an appropriate Aids policy as well as care of the ill. In their handling of Aids it was seen once again that the potential for self-help cannot be strained to simply any arbitrary extent: after a period of great commitment the front weakens. While some of the people in a movement turn to other topics, others succumb to an undertow in the direction of professionalization and institutionalization. The process of transformation from informal to formal help that takes place in the wake thereof – from self-help to welfare facilities – alters the nature of the NGOs: to a certain extent they 'normalize' themselves and become an integral constituent of the welfare state and are now subject as well to the way the latter functions (Rosenbrock, 1994a). That is usually tied to depoliticization.

### 3.2 *Aids-specific driving forces of normalization*

**a.** In western European countries, at least, the horror scenarios originally painted about the spread of the epidemic have failed to materialize. Aids in this region did not turn out to be a new scourge of mankind and will probably remain controllable in industrialized countries in the future as well. This is indicated, for one, by the fact that the basic epidemiological patterns have remained constant in the individual countries. The brunt of the disease is borne – with a wide north-south spread – by the groups primarily affected: by men who have sex with men and IV drug users. This is largely perceived as a restriction of the risk to marginal groups, which enhances the tendency of the general public and political representatives to sound a *de facto* all-clear and thus encourage normalization, despite frequent messages to the contrary (Berridge, 1996).<sup>6</sup>

**b.** While exceptionalism was based decisively on the fact that medicine was on the defensive and had nothing to counter the unknown disease with, first successes are now starting to be seen: due to the greater knowledge and larger number of therapeutic possibilities rendered possible by medical research, Aids is increasingly becoming a manageable disease in individual terms as well. The successes achieved may remain limited, remarkably increasing in possibilities of treatment without improvement in the prospects of a cure.<sup>7</sup> But to the extent the disease becomes treatable and the medical profession's options for action rise, two processes that give normalization substantial thrust begin to take effect. Medicine once again becomes a decisive instance in the struggle against the disease. If Aids formerly led to repositioning within the structure of the health-care professions involved in the fight against the disease and there is renewed mobilization of the medical profession's feasibility myth that was initially placed in question by Aids, medicine again claiming an authority to make definitions and exert power that goes far beyond its field of competence. A reconfiguration of the actors' set of circumstances now ensues: non-medical health professions – e.g. nursing or social helper professions – again lose importance and the ability to shape affairs. At the same time, medical tasks that go beyond the control of somatic processes tend to be neglected again, and a routinization process begins.

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<sup>6</sup> Heterosexual transmission not involving the participation of one of the groups mainly affected is continuously increasing from a very low level despite prevention efforts that are currently on the downturn. The hazardous potential for society in general (if no vaccination is found) is apparently too long-termed to truly frighten people.

<sup>7</sup> In view of the foreseeable necessity for lifelong therapy and the still comparatively short periods looked at as well as the related risks of the development of resistance and long-term undesirable effects it is, of course, necessary to warn against therapeutic optimism. In the early 90s AZT was also celebrated as a therapeutic breakthrough, and far-reaching consequences, e.g. in respect to the HIV antibody testing of people without symptoms, were propagated as the gateway to early treatment. References to inadequate evidence for such an assessment, on the other hand, were not accorded appropriate attention until after the euphoria had generally abated (Rosenbrock, 1994b). Currently, too, there is no lack of people voicing the vagaries and risks of the new therapies (e.g. Volberding et al., 1998; Gill et al., 1998). The public perception of a therapeutic triumphalism (Bayer, 1998; Steffen, 1998) is hardly impeded thereby.

c. With the increase in therapeutic possibilities Aids representation changes and is increasingly perceived and managed as a chronic disease. It displays all the structural features of this type of illness (longevity, long course of events, inconstancy) and thus takes its place in the spectrum of today's dominant diseases in wealthy countries (Fee/Fox, 1992). Thus, for example, the patterns of the course taken by the disease change: if survival with full blown Aids amounted to only a few weeks and months on average when Aids first cropped up, it already amounted in Germany, for instance, to 8.9 months in 1988 and in 1996 (i.e. just before the availability of combination therapies) to as long as 20.1 months (Hamouda et al., 1997). Many of the clinical pictures that initially led to death are treatable but leave behind irreversible functional losses and accompany the diseased person for the rest of his or her life. Now that Aids is turning into a chronic disease all those questions familiar to, though unanswered by, industrialized nations are making their way onto the agenda. In terms of health policy that suggests that Aids should be integrated into the spectrum and routines of problems with a similar nature.

The possibly most significant step, for the time being, from normalization to a normality of Aids as a chronic disease came from virology and clinical medicine. In the perspective of the described development lies the hope of rationalizing major Aids-policy conflicts and returning to a routine of "technical responses" (Thiaudiere, 1998). This development - as shown - runs up against an Aids community that is already smaller in quantitative terms and, in qualitative terms, is no longer occupied with expansion and consolidation but with defending the status quo reached under exceptionalism.

d. If in times of exceptionalism Aids triggered great willingness to take action and spend money, a willingness that remained constant for a long time, it is now possible to see - once again within a staggered timeframe - a decline in the preparedness of actors in the government, welfare state and health care system to enter into political and financial commitments for Aids. In many countries state-supported programs are coming to an end, others are successively being cut back and Aids is beginning at the same time to be integrated into normal funding - though usually on a tighter basis due to cost-containment strategies. In the course of normalization dependence of Aids policy on customary health policy grows ever greater, the issue is integrated into this arena again and subjected to what is increasingly becoming an economically restrictive perception and financing logic. The funds for prevention and research are in most countries also shrinking to a fraction of their previous level (Balter, 1998). The thematic focus is shifting at the same time: in research money is going mainly to medical Aids research, with funding being cut back for the social sciences (exceptions: Switzerland (cf. Bühler/Waldvogel/Zinkernagel, 1997), France (cf. anRs, 1998)).

e. Many pioneers committed themselves to Aids because for them the disease was not an abstract artifact but a concrete threat. The constant confrontation with physical and mental decay, dying and death, soon led to overloads and burn-out phenomena (Moers/Schaeffer, 1992b; Kleiber et al., 1995; Bayer/Oppenheimer, 1998). Especially

in the NGOs, but also in many of the care facilities specializing in Aids, it is not only the dying of others that characterizes everyday life; many of the once committed Aids activists are also dying. The subject of dying and death thus determines everyday life as in hardly any other field of care; on the one hand it evokes to unimagined extent great solidarity and willingness to act, while on the other it leads to special signs of exhaustion that not rarely end in the field being abruptly abandoned or in the desire for 'professional distance'.

#### **4<sup>th</sup> phase (starting about 1996): Normalization/normality - interim results and perspectives**

In comparison to the Aids health-policy model that had made exceptionalism possible (cf. above, section 2), health-policy reality presents a contradictory picture at the end of the 1990s as a result of completed and current normalization processes: On the one hand, Aids-related task forces and specific government agencies are being cut back or (re-)integrated in normal hierarchic/bureaucratic organizations (Cattacin, 1998). Some of the resources for prevention and research are being drastically reduced. Such cutbacks are in part being made as a reflexive response to declining and/or originally overestimated pressures, and thus justifiably. In part, however, this is being done at the expense of prevention efficiency and the quality of care - normalization in the form of cutbacks. On the other hand, Aids-related innovations have gained acceptance and have become institutionalized - normalization as the stabilization of exceptionalism. Finally, Aids has also kicked off developments that have not only stood the test in respect to Aids but have also become generalized as a new normality - normalization as a generalization of exceptionalism.

Examples of stabilization, cutbacks and generalization as well as numerous mixed forms are to be found in all of the policy fields touched on by Aids. In the following this will be sketched using examples of three policy fields strongly shaped by Aids: patient care (4.1) stands in this connection for the medically dominated core area of old health policy, prevention (4.2) for the core area involving not only the modernization called for at the latest since the Ottawa Charter of WHO (1986) but also the handling of IV drug users (4.3) as a relatively independent spin-off field of health, criminal and social policies.

##### ***4.1 Aids patient care - normalization in the field of tension between innovations and (re-)medicalization***

In the care of people with HIV and Aids exceptionalism brought forth a large number of successful reforms with generalizable perspectives (cf. above, section 2.1). In respect to these innovations being taken back, consolidated and, in better cases, generalized it is possible to see different paths emerging; the direction of some developments still appears to be an open question. Seven aspects can be cited to outline this:

a. In western European countries today, people with Aids can reckon almost throughout with proper treatment that is available in both geographical and social terms; although with some differences between North and South and urban versus rural areas.

More contradictory and uncertain in terms of perspective is the development of a health-care structure in respect above all to other health professions that are no less relevant in view of the fact that Aids is turning into a chronic disease. The pivotal point of this development is the position held by medicine. Its position of power, a relative one that depends not least on its respectively available therapeutic services, is expressed not only in individual day-to-day care matters but also in its influence on changes in and the institutionalization of the care structure, up to and including the flow of funds for research.

In the exceptionalist phases this position of power was initially on the side of the innovators: with the appearance of Aids, medicine became the driving force (next to the potentially affected themselves and the exceptionalist alliance) behind the realization of patient-oriented care. In this connection it displayed innovative potentials and revealed strengths under stress (Bayer/Oppenheimer, 1998) of which it had long been considered incapable. As therapeutic possibilities grew and their options expanded, the extent of patient orientation reached began to crumble. Since then the trend has been to place more value on the necessities attached to the treatment of acute medical problems than on patient-care aspects. In other words, there has since been a shift in priorities from "care" to "cure", with utilitarianism increasingly determining the course of events (Schaeffer, 1998). Conventional routines are spreading and a process of medicalization is expanding: the focus is again on the disease and its susceptibility to treatment, and the sick person tends to disappear from sight<sup>8</sup>

In the course of this development medicine once again claims the power to define and shape policies and recaptures the external resources it appeared to have lost for a number of years<sup>9</sup> As a consequence, other health professions (nurses, psychologists,

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<sup>8</sup> This is understandable when one looks at the burden carried by medical Aids professionals: for them the greater number of treatment possibilities represent, on the one hand, a great relief that ameliorates their constant confrontation with futility, dying and death. At the same time, they are subjected to stress arising from precisely the same process, though it may be of a different kind: patients come for a far longer period of time, and they come more frequently. They are relatively helpless vis-à-vis the increase in the number of patients and their problems as well as the long-term nature of the relations with their patients, relations for the regulation of which there is a lack of concepts. Seen in this light, recourse to traditional routines must be understood as an attempt to cope with this dilemma (Bayer/Oppenheimer, 1998).

<sup>9</sup> In view of the rapid transition in many places – or to put it better: step backwards – of Aids patient care to the status quo ante normality, that, in particular, can have fateful consequences: apart from special developments, e.g. in France (anRs, 1997) and Switzerland (Office fédéral, 1998), only medical research is being supported to any notable extent by the state (Balter, 1998). In respect to ratios it must be remembered, that in Germany, for example, federal support for social scientists' research did not begin until 5 years after it first went to biomedical research and at no time amounted to more than a tenth of the total public spending on Aids research (Kießling/Vettermann, 1995). Research funding possibilities are lacking even for other fields of health policy from the

social workers, etc.) and community organized services of no less significance for the care of the ill lose importance again.

**b.** In many countries Aids has led to a modernization of, i.e. less restrictive patient care. In the course thereof innovations with a relevance extending far beyond Aids were tried out and implemented; in the meantime they have moved into other areas of care. Examples are, say, the great increase in rooming-in at hospitals, patient-friendly reorganization of infectious-disease departments in hospitals, involvement of informal helpers and NGOs, etc. in the care structure. Many of these innovations owe their existence to the commitment of well organized Aids patient-interest representatives who claimed and asserted rights to this extent for the first time. They are, however, primarily oriented to the initially dominant group of patients: middle-class homosexuals. In the case of other groups, e.g. members of the lower classes, migrants and, above all, IV drug users (cf. below, section 4.3), one can see deficits that are becoming increasingly difficult to cope with because the issue and its actors have lost their thrust due to normalization (cf. above, section 3) (Schaeffer, 1995a, 1995b).

**c.** Despite the severity of the disease, care is provided primarily on an outpatient basis. Its realization has produced sensational successes in many countries. In many places it was possible for the first time to provide such far-reaching outpatient care to such an extent for a complex and severe disease. This shows in exemplary fashion that as a result of Aids it was possible to tackle many central, structural deficits also blocking adequate care for other diseases. This also holds true for psychosocial care and the strengthening of an indispensable pillar of care that permits patients to remain in the environment they are accustomed to: outpatient care. It was included as a constituent element of health care, and in countries with a poor tradition of nursing professionalization (Germany, Austria, France) it acquired, for the first time, a standing in line with its importance for patient care. But here, too, it was seen that outpatient care found it difficult to adequately fill the position that had devolved upon it (Moers/Schaefer, 1998; Schaeffer, 1996). This was aggravated in several countries by the gap between an essentially progressive Aids policy and the underdevelopment of nursing care, or by what were infrastructural deficits in the field of home care anyway – e.g. in Great Britain as well (Wistow, 1998). As a consequence, people who have contracted Aids can by no means be sure of finding an adequate quality of care in the outpatient sector. In some countries innovation as a whole is threatening to grind to a halt (for Germany: Schaeffer, 1997; in contrast, for instance, for Switzerland: Bernardi-Schenkluhn, 1992). Due to longer life expectancies of Aids patients, that could lead to severe deficits throughout the entire field of outpatient care.

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perspective of the generalization of knowledge acquired with and about Aids. Patient-care research in most countries is still particularly underrepresented. That means that in many cases not even the preconditions for dissemination of this knowledge are met. A professionally handled transfer of knowledge that would be a necessary (but, of course, not a sufficient) condition for the dissemination and continuation of innovation (Rogers, 1983) can hardly come about in such a situation.

d. Questions relating to death and dying have been rediscussed in all areas of health care, and in many countries the hospice movement has been given new impetus by Aids. Furthermore, various concepts for the improvement of community-based care have been developed (Schaeffer, 1995a, 1995b). Nevertheless, it can be seen that despite these successes the care of Aids patients is inadequate precisely in the late stages of the disease and while the patient is dying. The expanded possibilities of medical treatment have led not only to care functions being pushed into the background but also to dying becoming medicalized. As with other illnesses, the time of dying for Aids patients is often accompanied today by maximum treatment intensity, in which questions involving the quality of life are more likely to play a subordinate role. The opposite phenomenon can also be observed: the tendency to hold in safekeeping those who are dying or who no longer respond to therapy instead of escorting them in humane fashion. The pressure to contain costs adds to the problem: looked at from an international point of view there is the danger that hospices could degenerate into a low-cost expulsion and catchment basin for patients who have to be shifted out of acute care.<sup>10</sup>

e. In respect to the overall care structure Aids led to numerous attempts to establish integrated and continuous care. To realize the same, new patterns of divisions of labor and new forms of cooperation were introduced in many countries. That applies not only to the relations between the professionals themselves and between professionals and informal helpers but also to the cooperation between, for instance, outpatient and inpatient institutions of care. The experience gained with these innovations shows it is possible to modify well-worn routines of cooperation and solve interface-related problems. But it also shows how quickly efforts at the same are threatening to flake off once again – either because they were not carefully implemented, inadequately secured in structural terms, confronted with rejection reactions on the part of the professions involved or because it was not remembered that cooperation also requires qualification (Bungener, 1996; Ribbe, 1998). That has consequences for the ill: inadequate harmonization and co-ordination lead not only to care discontinuities but also entail – above all in the late stage of the disease – a far-reaching destabilization of their situation.

f. For people with HIV and Aids (PWA) normalization mainly means a longer life, but – and this is the price of the disease becoming a chronic one – not a healthy life throughout or one free from professional intervention. This gain in time and the greater latitude to shape one's life face the challenge of also having to fill the same, i.e. having to normalize one's life, so to speak. Since then it is also possible to see a shift in priorities on the part of those affected: if during the period of exceptionalism

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<sup>10</sup> This can already be clearly seen in the USA. But it must also be viewed against the background that openly poor or nonexistent treatment of patients is a 'normal' state of affairs there that depends on their material resources (Bayer, 1998). For the countries mainly looked at here that poses, in view of neoliberally inspired health policies in Europe (Kühn, 1997), the strategic question of whether they want to or can maintain their historically evolved antidromic normality.

maximum priority was attached to a search for ways to continue living, problems of living with and despite HIV and Aids now have a far higher standing.

This trend has continued with the new therapy possibilities developed since the mid-nineties. The gain in life expectancy and in the calculable latitude to shape affairs has continued to grow, and – as people hope – a diagnosis of HIV no longer appears to be tantamount to an early end of life. It is only at a cursory glance that the coping demands made on PWA would appear to have lessened as a result of this development, for their survival depends on a very strict regime of medication. Not all PWA are in a position to cope with this situation in adequate fashion and deal with the medicalization of their life: many have problems adhering to therapy (van den Boom, 1998) and cannot handle the challenges of coping with the medicalization and ‘normalization’ of their life, challenges that are, by nature, contradictory. This applies especially to lower-class patients (Schaeffer, 1998). Moreover, a large number of PWA never benefit from the new therapies. That is the case, for instance, in the USA, where two-class medicine grants only some of the PWA access to the new and cost-intensive possibilities of treatment (Bayer, 1998), and even more so in the case of poor countries. Recently it has also been seen that the new therapeutic possibilities are threatening to lead to a renewed chronicity, with all the respective shifts in problems entailed thereby: not only are the rates of resistance to therapy rising but also the number of PWA who develop, for instance, brain diseases after a short period of relative stability.

Patient-care systems have not adequately adjusted to all these consequential phenomena of medical normalization or to the shifts in problems and needs that accompany every chronic turn of events. Thus, for example, the expansion of pharmacotherapeutic possibilities in medicine requires a higher degree of patient instruction and education as well as other patterns of interaction – not only between health professionals and patients but also between the health professionals themselves. Those are requirements that are not compatible with a return to conventional routines, and they also meet with deficits in competence. No less great, but of a qualitatively different nature, is the need for psychosocial support, a need confronted not only with the thinned-out ranks of these help professions arising from normalization but also with the fact that the remaining helpers are not adequately attuned to the new set of biographic circumstances (returning to work in a depressed economic situation, problems with insurances, etc.) or problems involved with PWA suffering from brain disease or adverse effects of new treatments. Nursing is also relatively helpless in respect to the longer life expectancies and various changes in the care required by PWA: on the one hand, these developments in countries with categorical services evolved in the course of exceptionalism – like, for instance, those in Germany – are forcing these services to shrink (Schaeffer, 1998). On the other, the regular community nursing and home care services lack adequate concepts because other sets of patient problems (old people and those with chronically degenerative diseases) and other structural challenges determine their everyday life.



In factual terms the progressive normalization of Aids in its chronic form demands from health professionals and health care services a new wave of adjustments and innovations. It is questionable whether they are in a position to do so. Their great and proven ability to react flexibly, to adjust and make innovations was linked to the existence of extreme pressures from the problems confronted, a greater latitude in the shaping of events and a high degree of motivation as well as willingness to act, and precisely that is disappearing with progressing normalization. Nevertheless, renewed adjustments are required if the maxims once followed - like patient orientation, need orientation, integrated and continuous care, a high degree of quality of care and life - are to be preserved and the priorities of professionals and PWA are not to drift farther apart. Moreover, looking back on the past experience gained in the handling of Aids it is already possible to predict that in the future as well every step on the path to normalization and every medical advance in the struggle against Aids will be accompanied by changes in not only the disease and its dynamics but also likewise in the quantity and quality of care needs and the patients' situations. Seen in this light, great willingness to adjust and flexibility will be a constant task - with and despite normalization.

**g.** The normalization of Aids also means the reintegration of Aids in the health-policy arena, and thus also the integration of Aids-related questions in the perceptual and financing logic of this arena. The further development of health policy in Europe is currently open, in terms of both the resources and the model used to guide it. Fears for the future of what were initially very extensively and powerfully developed models like, for instance, those of New Zealand (Lichtenstein, 1997), The Netherlands (van den Boom, 1998) and Germany (Schaeffer, 1998) result to considerable extent, and in some cases even mainly, from the consequences of market-oriented health care reforms with their consequences for the steering and funding of care benefits and insurance coverage. In the USA, on the other hand, it is possible to make out developments in which the exceptionalism achieved for Aids in the field of care funding is being called for in general (Bayer, 1998).

#### ***4.2 Aids prevention - between generalization, fatigue and retreat***

The primary prevention of HIV infection is probably one of the hitherto most successful case of public-related behavior modification in the history of public health. That is made clear by a comparison with the decades of far less effective intervention of the 'old public health' type in the prevention of sexually transmitted diseases and in respect to conventional health education for prevention in areas like cigarette smoking, nutrition, etc. The dissemination of "safer sex" and "safe use" messages that were socially and culturally adapted to target groups and organized with the respective communities has proved the feasibility, effectiveness and efficiency of 'new public health' and its superiority over 'old public health'. The behavioral changes are extensive and sustainable in both the groups mainly affected and the public at large, and can probably be improved even more in the event of consistent

further development (Bochow et al., 1994; Dubois-Arber et al., 1997a, b; Lagrange et al., 1997).

Primary prevention of HIV infection is based today on a broad foundation of knowledge in the fields of sexual science, behavioral sciences, milieu sociology, evaluation research, etc. This knowledge was produced in often surprisingly creative fashion with effective cooperation between the concerned communities' organizations, social scientists and state agencies. Numerous models of behavioral prevention were developed. In the course of this development the concepts became more refined: the original focus on risk groups shifted to risk situations. Different mixtures of motives were discovered behind risk taking and risk avoiding in such situations and often integrated into the design and implementation of prevention intervention: phases of life (e.g. youth), power structures (e.g. between men and women; between customers and sex workers), elementary psychological states (e.g. being in love), elements of life styles (e.g. meeting places, scenes), orientation of the relations involved (e.g. matrimonial, romantic, prostitution-like, hedonistic), types of social embeddedness (e.g. sexual networks), coping resources (e.g. health belief; self efficacy; sense of coherence), types of risk perception (e.g. danger vs. risk), sequestration experiences (e.g. stigma management) etc.. Though not all of this knowledge can go into practical prevention (Rosenbrock, 1996), it shows in sum what a large contribution social scientists' research can make to rendering prevention policies more effective (Rosenbrock, 1995b).

Generalization of this success for the prevention of other health risks is hindered not only by a lack of political will but above all by the fact it is difficult to clarify the factors which led to this success. What was the respective importance of

- the combined use of public-wide umbrella messages, target-group-specific campaigns and personal consultation organized by the groups concerned
- the quality of the messages and their communication
- the social climate based on a sense of solidarity that permitted publicly conveyed learning, even in areas involving shame and taboos
- the social cohesion in the groups affected
- the pressure exerted by mass personal confrontation with the consequences of the risk, i.e. with the HIV infected and Aids patients in one's personal surroundings?

Empirical research is confronted with the fact that practically all the 'tools' in all the countries are used in different ratios at the same time. That is why it is possible to measure only their overall effect with a number of methodological restrictions (Dubois-Arber et al., 1997a, 1997b; Carael et al., 1997).

Conceptual and practical problems of normalization in the sense of preserving and expanding these successes for the constant task of prevention arise, above all, at five levels:

a. If the risk of contracting a disease is distributed unevenly in terms of groups in a population, there is always the question of whether prevention should be directed evenly at the public at large or selectively at the groups mainly affected. In the first case it may be possible to avoid discrimination and probably, as a result, facilitate learning in general, but the groups mainly concerned will possibly receive inadequate warning. In the barely affected general public, on the other hand, superfluous fears will probably be aroused. But what speaks against the focusing of prevention on endangered parts of the population is the fact that simply because of their large numbers the sum of the individually minimal risks in the general population can, in the course of time, epidemiologically exceed the size of the risk among the groups primarily affected (Rose, 1992). This prevention-policy dilemma was aggravated in the case of HIV prevention by the fact that with gays, IV drug users and sex workers it was necessary to publicly address subgroups whose risks were greater than those of the general population by several powers of ten and who had been discriminated against not only because of the HIV risk or for the first time. It was feared that these groups' experience with discrimination and, in part, persecution could make it more difficult for them to accept state messages about changes in behavior or even block them. There was also the worry that the general public's willingness to discriminate against them could be heightened by public communication of aspects comprising these groups' life styles. In the course of normalization in most countries the pragmatic consequence was drawn from these dilemmas that target-group-neutral messages would be communicated to the general public by the government and/or public health services and that specific prevention would be left to the groups mainly affected, with state support of these groups' organizations. Only a few countries (e.g. Sweden: Henriksson/Ytterberg, 1992; Australia: Ballard, 1992) were operating, for instance, with a sexually positive and publicly visible message for gay men who have sex with men or IV drug users; in other countries (e.g. The Netherlands: van den Boom, 1998; France: Steffen, 1998) such differentiation on the basis of target groups would already have violated the policy of non-discrimination. On the other hand, this form of strict non-discrimination entails the risk that members of the mainly affected groups who do not identify with the respective community (e.g. closeted men who have sex with men; socially adjusted IV drug users) would remain left out of the flow of communication about their special risk. This dilemma also led to controversies in respect to the question of whether and, if so, in what way, for instance, gays and drug users should be excluded or prevented or discouraged from donating blood (van den Boom, 1998; Steffen, 1998; Taylor, 1998).

The normalization of Aids prevention has not yet yielded any conclusive solution to these prevention-policy dilemmas. But the debates that have already been intensively conducted on the subject at a high level made it clear that decisions in the field of tension between the efficacy of prevention, the realism of risk messages and avoidance of discrimination cannot be made on the basis of abstract epidemiological risk calculations either but always require pragmatic adaptation to national cultures,

in the case of HIV prevention, above all, to the way sex, drugs and minorities are handled.

**b.** From the very beginning of the epidemic it was and still is easier to formulate an appropriate prevention policy than to implement the same with successful politics within the scope of the given polity (cf. above, section 2.2). A substantial hindrance to effective HIV prevention was and is the moralization of the Aids risk stemming mostly from the state and/or churches. Countries like Australia, in which prevention was publicly called for and disseminated early on with positive sexual messages for gay men and sex workers, remained the exception (Ballard, 1998). In numerous countries there was constant state censorship of prevention messages that were too explicit in respect to sex or drugs. In some, above all southern European countries it is still difficult or even impossible today to advertise publicly, for instance, for safer sex and the use of condoms (Kenis/de Vroom, 1996; Cattacin, 1998). However, the normalization of Aids in every European country has led to greater latitude for public communication about homosexuality, promiscuity and extramarital sex (Wellings/Field, 1996), and this to a decline in – but by no means to the disappearance of – a double standard of morals and prejudices.

**c.** Not only in accordance with the ‘philosophy’ of WHO’s Ottawa Charter but also in quite practical terms, community-related prevention is particularly dependent on high and lasting honorary commitment (volunteering) from the respective communities. With different delays and to different extents the governments of all the European countries have, for all practical purposes, realized the resulting necessity to make volunteering possible and to stabilize it with state support. On the one hand, the support of community building and community organizing with state resources permits stabilization and professionalization of the organizations, but, on the other, it also leads to constant tension between a striving for autonomy and factual dependence, between honorary and paid work, between tasks of planning and implementation. In an international comparison an inverse relationship is seen between the extent of state support for Aids-related self-help organizations and the degree of legal regulation surrounding HIV/Aids (Kenis/de Vroom, 1996). The number of self-help organizations for gays, IV drug users and sex workers rose very dynamically in all European countries in the exceptionalist phases and has also largely remained stable in the course of normalization. But the normalization-related erosion tendencies (cf. above, section 3) also affect this part of the self-help movement dedicated to primary prevention. They are aggravated by the fact that the majority of Aids-related community organizations number not only prevention among their tasks but also social and legal support. Primary prevention is often in practical competition with these visible and personally attendant problems.

Several hitherto inadequately answered questions are therefore posed during the transition of community- and target-group-related prevention (though not only HIV-specific) to normality:

- What lobby, within the scope of a “welfare mix” (Evers/Olk, 1996) aimed at equity and efficiency, is needed by the volunteer-based part of the system of social health assurance to obtain public support that would also safeguard its existence in times of keener distribution struggles in the welfare sector and/or declining exceptionalism? (political sustainability)
- What mixture of material and immaterial incentives is required to obtain, qualify and maintain an adequate influx of motivated volunteers? (incentive mix)
- How is it possible to counteract the tendency of self-help organizations to concentrate on the relatively easy-to-reach parts of target groups and to neglect hard-to-reach populations? (coverage of underserved populations)

**d.** It is precisely the last question that is becoming increasingly topical and thorny: at first, mainly homosexual men from the (more mobile, autonomous) middle and upper classes appeared to be impacted by HIV and Aids. The first generation of prevention activists also drew its energy mainly from this group, but it not only tackled prevention for its own community but also helped, for instance, to organize prevention for more poorly organized IV drug users. In the early 90s it was already noted in the USA that the slowing spread of the epidemic in this group reduced the activists’ motivation to organize primary prevention, that energy began to be devoted increasingly to questions of therapy and, especially, to the development, approval and distribution of drugs, prevention efforts for people of a lower socio-economic status tending to be neglected (Wachter, 1991). This tendency, which can also be found in patient care (cf. above, section 4.1), began somewhat later in Europe as well. Despite numerous important efforts to reverse the trend, Aids prevention increasingly became an event by middle-class gays for middle-class gays, with an additional bias in favor of men patronizing the commercial subculture.

This systematic deficit in community activities was tackled only hesitantly by the social scientists occupied with questions of prevention. Only at first glance is it therefore surprising that the variety and differentiation of prevention approaches outlined above did not match any similar development in regard to differences based on socio-economic status within the target groups (Luger, 1998).

This deficit is starting to take its revenge, since new HIV infections are increasingly occurring with disproportionate frequency in the lower classes in European countries as well. For Aids prevention, that poses the same questions confronting any health policy aimed at the reduction of socially caused inequality of health opportunities: how does the social situation determine or hinder risky behavior and preventive learning, especially when a risk that will occur after a long and uncertain future is to be prevented by today’s behavior (Rosenbrock, 1987a)? What influence does the socio-economic status have on self-assuredness, self-efficacy (Bandura, 1977) and sense of coherence (Antonovsky, 1987), on the chances for a stable (sexual) identity, on the ability to communicate and negotiate? What do information, information channels and settings have to consist of for these prevention obstacles to be tackled?

These important questions, which also go far beyond HIV and Aids, are just beginning to be handled in practical and scientific terms (Luger, 1998).

e. Competing with these efforts are attempts in the course of the remedicalization of the health policy sector to once again neglect primary prevention and give renewed interest to early detection and treatment (secondary prevention) or even post exposure prophylaxis. This implies intervention targeted to the individual, i.e. in terms of the HIV antibody test. After AZT medication for pregnant women infected with HIV proved to be capable of reducing the risk of vertical transmission from the mother to child by about two-thirds from approx. 30%, the first medically valid indication for target-group-related screening appeared to be given. With the availability of antiretroviral combination therapies since 1996 such proposals have once again increased and today are also being made in respect to gay men, hospital patients, age groups, etc. In discussions about the subject (e.g. de Cock/Johnson, 1998) and in attempts at implementation the disadvantages of the procedure (deficits in sensitivity and specificity of tests; HIV antibody test does not detect infections during the first 10 to 12 weeks, when the risk load in risk situations is much higher than later; the most endangered target persons not reached; limits to and uncertainty of the medical benefit; undesirable effects of the test; climate of trust disturbed) (Rosenbrock, 1991, 1994b) are hardly being looked at anymore. And, as was already the case with the discussion about tests in the first phase of exceptionalism (cf. above, section 2.1), aspects of medically indicated secondary prevention were intermixed with those of primary prevention. The return to (voluntary or compulsory) screening, case finding, compulsory partner notification and treatment, is frequently also called a return to proven principles of public health (e.g. Burr, 1997; Gostin/Ward/Baker, 1997; Lazzarani, 1998; more considerate: Colfax/Bindman, 1998; opposed: Horton, 1998) as if 'new public health' were not an improvement over 'old public health' but the betrayal of unshakable principles of public health as a whole. Without any adequate evidence (Gill et al., 1998a, b) HIV antibody tests are once again claimed to have a preventive, behavior-steering effect, as many HIV tests as possible being evaluated as a kind of indicator for effective prevention.<sup>11</sup> It is hardly ever

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<sup>11</sup> In this connection, for instance, the fact is overlooked that in Sweden, the only European country to have followed this philosophy for more than 10 years now, the compromise in effect there is presently crumbling in favor of 'new public health' at the expense of 'old'. The Communicable Diseases Act is to be scrutinized and revised since, despite massive advocacy of testing and a (cumulative) total of 9.5 million HIV AB tests for 8.5 million inhabitants (up to 1996), some 55% to 90% of new HIV infections are alleged to have been transmitted by people who were unaware of their serostatus and since, moreover, the coercive regulations are strongly biased against marginalized groups (i.v. drug users, migrants) of the population (Danziger, 1998). Maximization of the number of people tested for HIV antibodies, accompanied by the hope of effective primary prevention attached thereto without any further evidence, was also the main argument for approval of home collection tests in the USA (Philips et al., 1995). These hopes were not fulfilled, of course, the sales figures remaining far behind expectations (Karcher, 1997; Robert Koch Institut, 1997). In Europe this technical innovation is viewed with a critical eye, mainly because there is no evidence for improving the efficiency of primary prevention and because the possibility of pre- and post-test counseling is lost as a result (Rosenbrock, 1997a); the HIV home collection test has not been approved yet.

remembered that a very large number of human lives could be saved by primary prevention with the resources required for tests (Gill et al., 1998a).

People who have hitherto been test critics and liberals are also recommending greater testing as a means of better surveillance and a better allocation of resources in prevention and patient care (van den Boom, 1998). Here, too, the results of the discussions conducted in the 80s should be recalled: for the determination of prevention deficits (i.e. to focus on preventive measures) findings from screenings arrive too unreliably and with delay. Nor is it possible to use HIV antibody tests to evaluate the success of prevention measures with any greater degree of satisfaction. What is more, the indicators and predictors of risky behavior that are more important than the serostatus and/or infection rate for risk assessment in primary prevention can be determined by community-borne or social-science methods much more quickly and accurately to the extent required for the guidance of policy. Nor does planning of the capacities appropriate for patient care, in terms of quantity and quality, have to rely on determining the HIV serostatus of populations or groups. In addition, the (in most countries) anonymous infection and case registers, sentinel routines and the results of HIV antibody tests based on informed consensus provide enough 'vantage points' of various sub-epidemics which, when related to each other, permit a better epidemiological overview than any available for most other diseases, with the exception of cardiovascular ones (Kirschner, 1993).

In view of several discussions that are flaming up again within the scope of normalization, and above all in view of the role played by HIV antibody tests and screenings, up to and including compulsory tests, it would appear important to point out that the decision in favor of the basic model of Aids prevention policy was made both for reasons of efficiency and for the protection of civil rights (cf. above, section 2.1). This prevention model currently represents what is probably the most effective and efficient way to fight diseases that are mainly transmitted by sexual contact, a way that will not become obsolete because drugs are available to lengthen people's lives, because minorities have (so far) not been subjected to witch hunts or because the affected communities have been integrated into the political process (so 'going underground' no longer represents any central danger).

So far this debate has not assumed forms in any European country that could do any harm to testing policy, and by extension to prevention policy. A look at developments in patient care (cf. above, section 4.1) shows, however, that even soundly justifiable and practicable innovations can be watered down or even retracted in the course of the medicalization of Aids. To summarize the deficits outlined here, and with a view to developments in the usually trend-setting USA (Bayer, 1998), the participatory, community- and communication oriented prevention model of publicly organized learning must be viewed as an endangered innovation. This danger becomes more acute in a phase in which primary prevention would also require further development in conceptual terms as well: in view of the new therapeutic hopes, assessments of the magnitude of risks associated with an HIV

infection might decline and thus a motive for preventive behavior be weakened (Adam et al., 1998; Hubert et al. 1998a, b).

The risk of a failure would not only have a double impact on HIV prevention but also on modernization of prevention policy in general in industrialized countries: in the debates centered on the HIV antibody test, for one, standards have been set in respect to its effectiveness and efficiency as well as the desirable and undesirable effects of early detection (secondary prevention), standards that are still waiting to be applied to screenings for other diseases (Holland/Stewart, 1990; Miller/Lipman, 1996). For another, the currently most promising strategy of preventing diseases of civilization is at stake with the model of publicly organized learning.

#### *4.3 Aids and drugs – exceptionalism turns into normality*

Long before Aids, politics in the handling of narcotics, IV drug use in particular, comprised a relatively independent arena in which actors' networks, institutions and regulations from the fields of health and welfare policy as well as youth and criminal policies overlapped.

Since the 70s at the least there have been two contrary policy approaches competing with each other: repression and abstinence versus risk and harm reduction. The tools of the first are criminalization and the demand for freedom from drugs as a precondition for any help or therapy. The second policy works with needle-exchange programs (prior to Aids as well), low-threshold contact with drug users (street work) and methadone programs. Representatives of the repressive line argue at heart that only a war (of extermination) waged on drugs is appropriate or even promising of success. The main argument propounded by advocates of a risk-reduction policy is a pragmatic one to the effect that illegalization does not generate abstinence; it drives users underground, and the problem becomes utterly uncontrollable. In respect to the goal of preventing drug dependency as well as the health and social misery it causes, none of these approaches have any truly smashing success to show for themselves that would put an end to the controversy with empirical evidence. Both sides blame deficits in the implementation of the respective policy approach for the failure of such success to materialize. The fact that central moral values of western industrialized societies are touched on with the subjects of 'intoxication' and 'dependence' also plays a role in keeping the topic high up on the political agenda.

When it became clear before the mid-eighties that the sharing of HIV-contaminated needles represented the most important path of transmission for the HI virus after sexual transmission, the political arenas of Aids and drugs began to overlap. In this phase Aids policy was just in the process of abandoning the repressive 'old public health' paradigm and increasingly committing itself to the inclusion and cooperation model, i.e. that of community-based publicly organized learning strategy (cf. above, section 2.1). It is evident that this model is only compatible with the harm-reduction



approach, and not with repressive drug policy. Thus its implementation faces great difficulties in the context of a repressive drug policy. As a consequence, an alliance was arrived at by the dominant part of the Aids arena with the harm-reduction coalitions of the drug-policy arena, the strength and composition of which differed, of course, from country to country. Since Aids, as a more prominent subject, was the 'mightier', a policy window was opened up in this set of circumstances for implementation of harm-reduction strategies, at least in countries with a predominantly repressive drug policy. In terms of arguments they had an advantage in as much as the debate focused right from the beginning on the pragmatic question of how to bring about a maximum reduction in risk situations, given the hazards posed by Aids (Rosenbrock, 1986). The questions that gave rise to ideological controversies, namely whether and to what extent drug use should be viewed as an illness, crime, voluntarily deviant behavior, socially related evasive behavior, provocation or protest, tended to play a more subordinate role as a consequence.

To understand the national differences in the way Aids and drug policy mutually influenced each other it is necessary to take a look at the different initial positions.

In France there was and still is a basically unbroken tradition involving a strong state policy of repression (Steffen, 1992, 1996) with a growing softening tendency since the 1997 change of administration (Steffen, 1998). Germany has a similar tradition but is experiencing a remarkable change in policy toward harm reduction within the scope of the challenges posed by Aids (Frankenberg, 1992). Similar remarks apply to Switzerland (Kocher, 1993; Gutzwiller, 1995; Staub, 1998). Great Britain was pursuing a more liberal drug policy prior to Aids and also implemented risk-reduction programs at a very early stage (exchange of needles, above all) (Taylor, 1998). Italy has liberal legislation, but state programs have hardly been implemented. In the private sector, on the other hand, welfare organizations steered by the influential catholic church are exercising a repressive drug policy. Risk-reduction strategies are to be found in only a few politically progressive municipalities and private institutions, above all in the north of Italy (Cattacin, 1998). The Netherlands (van den Boom, 1998) already had a liberal drug policy prior to Aids, similar to Great Britain, and have built their risk and harm limitation strategies on the same within the scope of their Aids policy.

All in all, it can be seen that in the adjacent or overlapping field of drug policy Aids exceptionalism has brought about movement in the direction of or consolidation of harm-reduction strategies in every country - with the exception or 'late arrival' of France. In this respect, however, it is also possible to see remarkable differences between the countries in regard to actor configurations and politics.

In France Aids exceptionalism unfolded late. This special development of what was essentially an unbroken policy of abstinence can be explained by various factors: the politics of Aids prevention banned procedures specific to target groups (Setbon, 1996), since that was viewed as discrimination (cf. above, section 4.2). That weakened the impact of Aids policy on drug policy. Government policy did not abandon the

abstinence dogma for fear of moral/fundamentalist coalitions, i.e. for reasons of election tactics. In the end, professional drug helpers rejected a merger with Aids prevention and care since they feared a medicalization of the drug sector (methadone programs, etc.) and thus a loss of institutional autonomy. This situation changed under the pressure of a coalition between different health professions that accepted the principle of harm reduction and finally supported it.

On the other hand, non other than the alliance with medicine that failed in France made it possible to turn drug policy in a different direction in Germany. The 'liberal scare' about Aids also made it possible to develop new therapies for i.v. drug users within the scope of target-group-specific prevention campaigns. In this way some physicians were won over to the idea of once again accepting as patients for methadone programs the drug-user clientele they had regarded as resistant to therapy since the 70s. The strong reputation of the medical profession with the public and government was what first made it possible for politicians to move away from the dogma of abstinence (cf. Moers/Schaeffer, 1992a). It was much more difficult, however, to implement non-medical intervention, above all needle exchanges. Within the framework of street work the exchange of needles was first introduced in the public realm through activities in model programs and self-help (above all the Deutsche Aids-Hilfe). Most institutions and prisons, on the other hand, are still denying any need for liberal action. They are sticking to the official ideology which states there is no sex or any consumption of drugs in prisons because, after all, that's not allowed.

In Switzerland it was the combination of the threat posed by an unchecked Aids epidemic with a relatively high prevalence of IV drug users which helped to overcome the dogma of abstinence and implement programs that went so far as the controlled distribution of heroin (Klingemann, 1996). But - in comparison with Germany - self-help organizations and the public health sector are involved to much greater extent (Staub, 1998). This coalition was strong enough to fend off renewed attempts to establish a policy of abstinence and was able to push through modernization more consistently in general (Gutzwiller, 1995).

In Italy the weakness of both state and municipal institutions led to a marked undersupply of preventive and therapeutic possibilities for IV drug users. This gap is being filled, if at all, by the catholic church and its affiliated organizations. With their call for abstinence in respect to not only drugs but also to sex not intended for procreation they in part contradict state policies and messages. The effectiveness of both Aids prevention as well as the prevention and therapy of addiction is diminished by this continuing contradictoriness (Cattacin, 1998).

In Great Britain, on the other hand, the emerging Aids crisis gave a massive boost to what were already exemplary risk-reduction strategies (above all needle-exchange programs). Public health professionals and the national health service, which at that time was in the process of going through reforms involving a strengthening of local organizations, promoted this development, while state policy tended all in all to

handle the subject of Aids with hesitation and tacking. Here it was therefore possible to make partial use of existing public health structures to consolidate harm-reduction policies, even though at the same time a more repressive governmental policy generally prevailed, a policy that was expressed, for instance, in strong homophobia with correspondingly discriminating laws (Taylor, 1998).

An essentially similar picture is provided by The Netherlands. There it was possible to successfully link a drug policy already devoted to the harm reduction approach to Aids initiatives. Unlike Great Britain, this line was supported almost throughout by the government, which put its money on what was, all in all, a liberal, participatory and coherently planned policy (van den Boom, 1998).

When the various political strategies are compared with the epidemiology of HIV infections and/or cases of Aids linked to IV drug use, it seems only natural to see a success in the risk-reduction strategy: Great Britain, Germany and The Netherlands have, in comparison to Italy and France, far fewer cases in the drug sector. Countries like Portugal and Spain, which have taken a similar path to Italy, have high percentages of HIV infections arising from IV drug use. Caution in the interpretation of the epidemiological figures is, of course, called for: in southern European countries the IV use of drugs is in some cases far more widespread than in their northern European neighbors (Hamouda et al., 1997), and a country with a liberal drug policy like Switzerland has quite a high incidence of HIV infections related to IV drug use (Staub, 1998). The latest tendency is for southern and northern European countries to drift farther apart in terms of the pattern exhibited by the spread of the Aids epidemic, with a distinct increase in the percentage of IV drug users accounting for Aids figures in the south of Europe (Robert Koch Institute, 1998).

A liberal or repressive drug policy was therefore either expanded and stabilized under the influence of the Aids crisis (Great Britain, The Netherlands), revised (Germany, Switzerland) or kept up (France, Italy). In this respect Aids exceptionalism in some countries (Germany, Switzerland, Great Britain) brought about a change in policy even where a conservative government policy would not necessarily have led such to be expected.

A look at the transformation of drug policies in the context of Aids policy yields the following picture. In the phase of policy formulation and emerging exceptionalism the drug policy existing prior to Aids is essentially continued to begin with, i.e. a liberal or repressive one. In the phase in which exceptionalism is consolidated corresponding, liberal programs are formulated and, for the most part, also implemented in most countries. In the phase distinguished in other areas by crumbling exceptionalism an ever broader liberal consensus is gradually able to gain acceptance in drug policy – the normalization of drug policy triggered by Aids has taken on a life of its own, and the harm-reduction coalitions in this policy field have gained decisive strength because of Aids. In countries that already have a liberal tradition harm-reduction programs are expanded, above all from needle-exchange programs to substitution and the isolated distribution of heroin. In France, a cautious

reorientation of state drug policy toward simpler access to sterile needles (for sale in drugstores, etc.) and to easier access to methadone programs is in the early stages. Since 1997 the socialdemocratic administration has been cautiously softening the abstinence dogma, thus liberalizing the processes taking place anyway in everyday prevention and therapy (Steffen, 1998).

What is characteristic of drug policy in all the countries not explicitly pursuing a harm-reduction strategy is a field of tension between national programs and practice. Government and international declarations ('war on drugs', etc.) emphasize the principles of abstinence (cf., for example, the 1997 debate conducted in the EU about a ban on the sale of cannabis in The Netherlands: van den Boom, 1998). On the way from government programs, operative instructions for and from public authorities to the work done by hospitals, medical practices, therapy facilities, self-help institutions and street workers, these principles tend to become diluted, to vanish or to turn into harm-reduction approaches. It remains to be seen whether this often effectiveness-reducing tension will lessen or even disappear in the course of the normalization of drug policy additionally promoted by Aids. The course of events to date gives cause for this hope: in Europe, drug policy on the whole can be viewed as a trend toward normality in which not only the requirements of Aids prevention are taken into account. Indeed, the 'Aids case' has become the midwife of more general social modernization measures which, due to the liberalization of narcotics consumption, have been on the agenda ever since the 70s at the latest.

While drug users and drug addicts in Europe can, on the average, now hope for more realistic, humane and effective treatment as a result of the Aids crisis, the new possibilities of medicinal treatment are also leading to new problems for this group. While, even in cautious estimates, a liberal drug policy with low-threshold possibilities can point to successes in the reduction of risks and harm, the new combination therapies require an unusually high degree of adherence to treatment, for which the reality of the life led by drug users, the homeless or sex workers does not exactly create the best preconditions. What would be necessary here are new outreach strategies that integrate medical and social care, strategies that are not provided for in medical-care structures that still exclusively require people to come in for help. Possible approaches for a strategy involving the monitored taking of Aids medication would be links to methadone programs, but they also have a structure which requires people to come in for help. The results of projects and investigations involving the problems of adherence to therapy on the part of IV drug users with Aids remain to be seen. Normality in the medical care of these patients therefore does not in any way yield a positive picture similar to that of drug policies themselves. Rather, there is the threat that the "normally poor course of health policy" (Rosenbrock, 1986) will be continued, thus leading to continued discrimination of already marginalized groups of patients.

## Conclusion

In every European country the rise of Aids led to important and profound innovations in the fields of prevention, patient care, health policy and civil rights. Compared with the usually sluggish and merely incremental reactions to other health-related problems, these innovations can be called exceptional. This exception from the normally poor course of events taken by health policies can be explained for the most part by the political thrust that fed on the fact that not only a health catastrophe but also civilizational harm in the field of civil rights was feared. Despite all the national differences in basic patterns, this combination brought about a like alliance of health professionals, social movements and persons affected that made political use of the latitude resulting from a lack of effective therapies.

A population-wide catastrophe in terms of both health and civil rights failed to materialize. The reasons for this are to be found not only in initial overestimates of the risks, the magnitude of which was assessed more realistically as medical and social-science knowledge grew, but also in the prevention-policy and civil-rights successes of the exceptionalist alliance. European countries, thanks to exceptionalism, were largely able to meet the Aids-related civilizational and health-policy challenges confronting their respective populations. National differences can be explained by the variance of polities and politics involved and by the respective strength of the "exceptionalist alliance" in relation to the inertia of primarily conservative, moralizing institutions. The variance in the institutionalization and legal framing of exceptionalism achieved in this field of tension will largely determine the direction and extent of further normalization, with all its national and policy-field-specific differences. It is not so much concepts as strength that is missing for a 'second wave' of innovations that would be desirable from a health-science perspective for consolidation of the exceptionalist model in prevention and patient care (Schaeffer, 1995b).

In this respect three basic but different forms (and many mixed forms) of normalization are emerging in this as yet incomplete process.

In part, policies developed within the scope of exceptionalism are being generalized (normalization as generalization). In the field of patient care, for example, application of the principle 'outpatient before inpatient', which has been practiced in very difficult conditions, the development of community-based and categorical services as well as patient-friendly organizational developments led to innovations that had a 'contagious' effect on the care of other groups of patients. Another example of this is the triumph of health-promotion approaches – though so far based more on programs than on practice – which are not restricted to simple appeals for modification of behavior but include the social determinants of health and health-related behavior. Here, exceptionalism has had an enriching and broadening impact on another current of public health policy. In the field of drug policy, after all, the

impetus provided by exceptionalism tilted the scales in favor of the development of pragmatic policies of harm reduction.

In other areas the special handling of Aids is being institutionalized (normalization as stabilization). This can be seen, for instance, from the categorical services still left in patient care, from the institutionalization of target-group-specific HIV primary prevention and also from changes in the definition of tasks and in the structure of state public-health institutions.

Certain programs and institutions that gave rise to exceptionalism are being cut back in the direction of the status quo ante (normalization as regression). In numerous countries special organizational units in governments and public-health institutions were and are being dissolved or reintegrated into general structures. In view of the problems requiring long-term attention this is usually realistic (and, due to the transfer of experience, can even provide stimulus for normalization as generalization). What is dangerous in terms of health policy, on the other hand, is the reduction of funds going to primary HIV prevention in absolute terms in some countries, e.g. in Germany. The development of structurally sustained communication and learning strategies for people at risk in the lower classes, where new infections are increasing disproportionately, is particularly suffering (Luger, 1998). A regression to 'old public health' policies is currently less likely to take place in Europe than in the USA, but it must be taken seriously as a latent hazard. The growth in therapeutic possibilities is leading to regressive tendencies in the field of patient care. There, the degree of patient orientation achieved is in peril. The cutbacks and, in some cases, nearly abrupt cessation of social-science and public-health research programs for prevention and patient care are worsening the preconditions in some countries for stabilization of what has been reached, let alone for generalization of the successes achieved with Aids exceptionalism.

From an analysis of Aids exceptionalism it is possible to draw four provisional conclusions about the development of health policy in the wealthy capitalist countries of Europe. Their validity and generalizability will have to be examined not only with further research on other risks and/or diseases but also with deeper international comparisons:

**a.** Policies and politics of Aids confirm the experience that in itself health may be a morally strong motive but in regard to political action it doesn't tend to be a sufficient one. Attention to health policy, the willingness to spend money and the strength to make reforms usually do not take their orientation from epidemiologically defined priorities (Levine/Lilienfeld, 1987). Profound reforms in the field of prevention and patient care in particular usually require that the health issue be related to important concerns - and corresponding actors - in other policy fields (Rosenbrock, 1998a.). If this condition is met, as it was in the case of Aids (civil rights), it is possible for modernization to take place in waves that would hardly be

possible so speedily and to such extent with the incrementalism customary in Europe in this policy field.<sup>12</sup>

Leaps in health-policy development in the sense of new perspectives and/or paradigms then become possible as well: next to the practical (and now endangered) transition of health care to need orientation in patient care it is necessary to point out, above all, the underlying change in primary prevention: community-oriented publicly organized learning strategy was originally developed for the prevention of chronically degenerative diseases, mainly of the cardiovascular kind, but it was barely able to establish a lasting foothold outside of model projects (DHP, 1998). Instead, the breakthrough, and thus the resulting change in perspective from the individual to the group and/or community, from behavior to the circumstances of people's lives, was achieved by this approach with Aids as a predominantly sexually transmitted contagious disease. The fact that this was politically possible and was also successful in practical terms forms the core of Aids exceptionalism. The renunciation of force in individually oriented search strategy ('old public health'), which is often viewed as much more spectacular, is in relation thereto only one ancillary condition – albeit a necessary one.

**b.** The chances of pushing through and implementing such leaps in innovation depend, however, not only on the thrust of their advocacy coalition but also on the conceptual and profession-policy strength of the approach to be tackled. In the case of Aids it has been seen that an apparent absence of effective treatment can delegitimize the power of medicine to define matters, at least partially and for a while. At the same time, that means less medicalization of the trend toward individualization and social control inherent in health-related problems (Zola, 1972). The temporary retreat of medicine from its customarily dominant role, which opens up room for other approaches, makes alternatives visible and testable. In primary prevention that holds true for the retreat from individualizing approaches. In seemingly paradox fashion, however, this configuration in patient care led to greater individualization of patient treatment. This was rendered possible, above all, by the greater assumption of care-related tasks and competence by non-medical health professions (nurses, social workers, psychologists, etc.) and informal helpers. Whether and to what extent related innovations and the upgrading of non-medical

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<sup>12</sup> The corporate transformation of health care, mainly in the USA (Salmon, 1990; Kühn, 1997), is impacting prevention and health care at a comparable rate of speed, and probably to a greater depth of penetration than Aids exceptionalism. What is involved there, however, can be seen as a special case of the connection between different issues and actors as a precondition for profound change in societies' dealing with health problems: the corporatization of health care became more dynamic to the same extent as patient care became more operationally calculable due to the development of statistical methods and data processing, thus becoming an interesting field for capital looking for investment opportunities. Once such a powerful connection is given, neither ethics nor morals seem to form insurmountable barriers against change. This is true for corporatization of health care, which – in keeping with the market-economy stimuli released thereby – is rather indifferent to problems of equity, as well as for Aids exceptionalism, which – dedicated to the principle of risk minimization – has overcome many traditional moral notions and concepts.

health professions will hold up or even be generalized in the course of remedicalization due to new medical therapeutic success in the case of Aids is an open question that will be decided in the end not at the sickbed but in profession-policy debates. The closer the innovations in question are to the core area of medical action in terms of organization and interests, the greater the danger posed by such normalization will probably be in the sense of a step backward.

c. Innovations in the social handling of health can exert considerable influence on other policy areas. That is not only true of drug policies but can also be seen from the greater tolerance toward and even increasing acceptance of openly homosexual men.<sup>13</sup>

The central message of Aids prevention (safer sex outside of strict monogamy) may not have led to greater promiscuity, as feared by some and hoped for by others (Dubois-Arber, 1998), but it did bring about a franker climate for communication about questions of sexuality and relationships. Finally, Aids exceptionalism also focused attention on several otherwise little noticed 'dark corners' of society: The light shed, for example, on human and social problems related to migration (Haour-Knipe, 1997), imprisonment (Turnbull, 1997) and prostitution (Delacoste, 1987; Aggleton, 1998) has given a hefty boost to the social-reform forces at work there.

d. Individually and with different time lags European countries have tackled and, on the whole, mastered their respective Aids crisis. There was and is more transnational cooperation between concerned groups' organizations (e.g. the European project on prevention among migrant sex workers TAMPEP, Brussa, 1996) and scientists (e.g. the two European research projects on sex research, van Campenhoudt et al., 1997; Hubert et al., 1998b) than at the governmental level of, say, the EU. Whether a better result would have been reached in Europe with more centralized decision-making structures than with the EU practice of general declarations and ad hoc research funding remains a question for which there are only speculative answers.

In view of the global Aids crisis, however, it is evident that European countries (with several relatively positive exceptions like The Netherlands (Moerkerk, 1998)) have failed just as much as the entire wealthy world. It is neither humane nor a sign of action in the direction of globalization and sustainability when in 1997 only some 10% of the world resources are available in developing countries, in which about 80% of HIV infections occur and Aids patients live and die (Morin, 1998). Despite many official declarations and attempts, from this point of view there has never been any Aids exceptionalism.

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<sup>13</sup> This finding holds true only with great differences between European countries. What is more, the development can by no means be ascribed solely to the Aids crisis. The discovery of gay men as a market segment with money to spend, and one susceptible to advertising, coincided with the occurrence of Aids and was the logical continuation of the successful gay liberation movement in market-economy terms (Rosenbrock, 1998b). The increasing public acceptance of gay men must, moreover, not hide the fact that there are still nationally specific differences; in Germany, for instance, there is a minority accounting for about one-third of the population with a strong sense of homophobia and a potential for aggression (Bochow, 1993; Dannecker, 1997).



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