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A CONTINGENT VALUE? THE CHANGING ROLE OF AUTONOMY IN LAW AND POLICY ON AIDS

von

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ABSTRACT

This essay examines the changing role of the ethical value of autonomy in law and policy relating to AIDS in a number of European jurisdictions. In the early years of the epidemic the autonomy of infected and at-risk persons, and of social groups was promoted as a means of reducing the spread of HIV in the general population. Accordingly autonomy was deemed worthy of respect for instrumental reasons. This means-end calculation was premised on the lack of medical therapies, as well as the need to avoid discrimination in order to prevent at-risk persons from going underground as far as health care systems were concerned. In law this instrumentalisation of autonomy was reflected in a specific application of the proportionality test, i.e. to impose coercive or discriminatory measures would be disproportionate, or even inimical, to the end of reducing the spread of HIV. This was a contingent analysis, strongly informed by the state of medical knowledge at the time, as well as by the relative power of professionals, health bureaucrats and lay activists. With the introduction of effective therapies such as Highly Active Retroviral Therapy (HAART) and Zidovudine (AZT) the terms of the proportionality analysis have changed decisively. As a result, it is now more likely than before that coercive measures will be implemented.

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1. INTRODUCTION

It is possible to view the history of AIDS to this date as a period in which the interaction between medicine and law was profoundly influenced by certain fundamental values and goals. Our concern here is with the fundamental value of autonomy and its relation to the goal of stopping the spread of HIV in European populations. Our purpose is to clarify the manner in which the ethical value of autonomy has resonated with contemporary public health strategies, and how this has in turn conditioned the application (and non-application) of legal measures in the face of the epidemic. The central figure of legal discourse through which concern for autonomy has been systemically linked with the goal of stopping the spread of HIV is the doctrine of proportionality.

In this piece we shall first distinguish two main justifications for the priority of respect for autonomy in ethics and law. These are the intrinsic significance of autonomy as definitive of human personhood, and alternatively its instrumental value as a means to the maximisation of other social goods. We then examine briefly the public institutional forms through which autonomy is protected in Europe. Chief among these are constitutional and legal guarantees of individual freedom, which have also been established in the European human rights order. Autonomy in the health care context is also indirectly protected by the codes of conduct enforced by the medical profession itself and through the increasing prominence of rights-oriented bioethics as a form of reflection upon medical activity. Having established the theoretical and institutional importance of the value of autonomy, we then examine its central place in public health responses to the spread of AIDS in most European countries. With some notable exceptions, commentators, activists and legislators supported a reflexive public health strategy which relied upon the informed, but unconstrained actions of individuals and social groups as the main means of containing the epidemic. Under this dispensation there was no significant role for legally backed coercion and repression. In other words, both normatively and factually, an instrumental respect for autonomy has been the dominant theme of AIDS law and policy in its first decade and a half.

We shall see that this dominance has been reflected in the interpretation and application of the relevant provisions of criminal, civil and administrative law in most Euro-

pean countries. In each case these rules have generally been interpreted as prohibiting secret and forcible testing, and compulsory treatment and detention. Even where the law is found (in certain jurisdictions or according to certain interpretations) to permit these measures, commentators have strongly advised against so proceeding on public health grounds. In each case, we contend, an argument based on the principle of proportionality is being deployed. This holds that autonomy must be protected through the enforcement of criminal and civil law rights and through the non-use of administrative law powers, in order to facilitate and encourage voluntary measures to deal with the spread of AIDS. It contends that coercion fails the test of proportionality because it is likely to be less successful, if not counterproductive, as a public health strategy. Both policy and law, therefore, justify respect for autonomy by reference to its instrumental usefulness in hindering the spread of HIV infection. The contingency of this position is demonstrated in the penultimate section of the present essay when we examine the impact of new therapies upon inherited public health policies and legal regimes. Therapy is now available for HIV/ AIDS, at least to the extent of securing a much longer life expectancy for the infected person. Given this advance it could now be argued that there is be considerably more to be gained from the imposition of coercive measures in abrogation of individual autonomy than was previously the case. As a result compulsory testing, detention and treatment may now satisfy the proportionality test. The new therapeutic regimes have also restored much of the power and prestige lost by the medical profession in the early years of the epidemic. We may expect, therefore, an increased use of biomedical disciplinary techniques quite independent of the enforcement of formal law. Thus, the instrumental justifications for the priority of autonomy in ethics, law, public health policy and medical practice are now more in question than they have been at any time since the early years of the epidemic.

2. PATIENT AUTONOMY IN EUROPE

a. Philosophical Basis

Autonomy is widely accepted as a value of central importance by writers on law, medicine and ethics, in Europe as elsewhere.[1] A rigorous philosophical treatment of the concept is beyond the scope of this piece. We may, however, note the significant aspect of self-government and freedom of choice which the value embodies. The implications of this elevation of autonomy for medical practice and health policy are clear. The original and proper source of authority for any procedure carried out upon an individual patient is the patient themselves.[2] Consent given by the patient is the only legitimate ground for almost any interference in their lives or any intrusion upon their person. He who deceives or coerces another, whether in medicine or elsewhere, usurps this self-government, replacing autonomous with heteronomous choice.[3] Given its social power and prestige, given its close association with the state, and given its potential to penetrate deeply into individual lives, medicine represents an ongoing threat to self-determination. In a time of infectious disease this threat is inevitably multiplied.

Both intrinsic and instrumental justifications are offered for the priority of autonomy in the ethical canon. If something is intrinsically valuable, it is held to be a good in itself.[4] Autonomy is intrinsically justified by the constitutive importance of self-determination and liberty to society and to individual subjects. On this basis it should be respected independent of context, and regardless of the positive or negative consequences of so doing. The right of self-determination is, thus, an almost absolute 'trump' against the abrogation of individual autonomy by state or private actors.[5] In medicine the derived requirement of consent functions as a firm constraint upon the reasoning and practical action of health care professionals and policy makers. By

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1 Cf. for example, I Kennedy, Treat me Right. Essays in Medical Law and Ethics (Oxford: Oxford University 1991) 385-413.

2 This position is developed by, HT Engelhardt, The Foundations of Bioethics (New York: Oxford University Press 1986).

3 Cf. TL Beauchamp & JF Childress, Principles of Biomedical Ethics (4th ed. New York: Oxford University Press 1994) 120-132.

4 This approach to ethical reasoning is more typical of continental European, than of Anglo-Saxon writers, cf. J-C Galloux, 'Ethique et brevet ou le syndrome bioéthique', Receuil Dalloz Sirey (1993) 83-90.

5 Cf. R Dworkin, Taking Rights Seriously (London: Duckworth 1977).

contrast, if something is instrumentally valuable, it is held to be good only and in so far as it is a means to some other, higher end.[6] Autonomy is instrumentally justified by those individual and social goods which tend to be produced when it is respected and promoted. This makes of autonomy a contingent value, which may be set aside or demoted where to do so would improve individual or overall welfare. Context and consequences are all. The right of self-determination is, thus, merely one, defeasible element among many in the calculus of general utility. In medicine there is general agreement on a core meaning for welfare: the physical and mental well-being of the individual. In the context of public health this is adapted to include the physical well-being, including freedom from infection, of the population as a whole. The autonomy of patients is to be respected in so far as it promotes their own health and that of their fellows. It need not be so respected where its exercise would be inimical to these goals. Decisions on this point incorporate and depend upon variable scientific data regarding the aetiology of disease and likely human behaviour. As these data are ever changing, such decisions are inherently open ended, revisable and reversible. We can already see the ethical form of AIDS policy-making in this. Should the rights of sufferers and those at risk be respected absolutely, or only on a contingent basis? If the latter, what are the elements of the welfare calculus? We know that they include the law, considered as both constitutive variable and dependent outcome. We also know that the law itself provides for comparative utilitarian reasoning through the doctrine of proportionality.

b. Institutional Basis

Respect for autonomy is also at the heart of the European legal order. It is reflected in the European Convention on Human Rights (ECHR) which enshrines the right to liberty and security of the person (Art. 5) and the right of privacy (Art. 8). At a national level, the German Basic Law of 1949 mandates the state to protect the dignity of the individual (Art. 1 I), as the well as the right of the individual freely to develop their personality (Art 2 I), their right to bodily integrity (Art. 2 II 1) and their liberty (Art. 2 II 2). In particular the right of personality has been held by the German Federal Con-

[6] Cf. TL Beauchamp & JF Childress, Principles of Biomedical Ethics (4th ed. New York: Oxford University Press 1994) 47-55.

stitutional Court to include a right to informational self-determination, meaning the right to decide when and to what extent personal information is made known to others'.[7] The United Kingdom Human Rights Act 1998 incorporates the ECHR into British law, making its guarantees an explicit feature of the latter for the first time.[8] It has also been held that the right of self-determination forms an immanent part of the common law.[9] The ancient writ of habeas corpus further testifies to the foundational value of individual liberty in the Anglo-Saxon tradition. However, these rights are nowhere without qualification. In the ECHR, for instance, Articles 5 and 8 are qualified by provisions permitting measures 'for the protection of health'.[10] German law also allows fundamental rights to be abridged, or indeed wholly overridden, where this is necessary to avert an imminent danger to the community or to more important rights of others.[11] In the United Kingdom, given the qualifications to Articles 5 and 8 ECHR, mentioned above, infectious diseases legislation would probably also survive scrutiny under the Human Rights Act 1998.[12] We shall see later that specific measures taken in the interests of public health are nonetheless subject to review having regard to their necessity and effectiveness. The law facilitates thereby a structured, instrumentalist calculation which may subordinate individual autonomy to the greater public health in a specific set of circumstances.

A discussion of institutional guarantees of autonomy would be incomplete were it limited to the rules of general (or state) law. As van Hocken and Ost have pointed out, 'instead of a legal system in the form of a hierarchized pyramid, law [may now be] presented as a network within which the places where law is created are multiplying'.[13] One important 'place' of this sort is the medical profession itself, which exer-

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7 Entscheidungen des Bundesverfassungsgerichts 65, 1 (42); for a general discussion, cf. HD Jarass & B Pieroth, Grundgesetz für die Bundesrepublik Deutschland - Kommentar (4th ed. München: CH Beck 1997) 65-67.

8 Cf. B Watt, 'HIV/ AIDS and European Human Rights Law' [2000] European Human Rights Law Review 54-65.

9 Sidaway v Bethlem Royal Hospital [1985] 1 All England Reports 643 (HL per Lord Scarman dissenting at 652c).

10 For an application of these exceptions, cf. the decision of the Commission in Acmanne v Belgium (1985) 40 Decision & Reports 251 (ECommHR).

11 Cf. HD Jarass & B Pieroth, Grundgesetz für die Bundesrepublik Deutschland - Kommentar (4th ed. München: CH Beck 1997) 277, 325-326 .

12 For a discussion of this point, cf. J Montgomery, Health Care Law (Oxford: Oxford University Press 1997) 37-39.

13 M van Hoecke & F Ost, 'Legal Doctrine in Crisis: Towards a European Legal Science', (1998) 18

cises a high degree of self-regulation in most European countries. Medical councils and tribunals, composed more or less of doctors themselves, promulgate codes of ethics and enforce professional discipline.[14] Traditionally such codes have emphasised technical competence, the dignity of the profession and loyalty as between doctors. More recently, in response to patient demands and broader cultural trends, there has been an effort to construe the duties of doctors in terms of the rights of their patients. Chief among these is the right to self-determination. Thus the French Code de Deontologie Medical states that

> Le consentement de la personne examinée ou soignée doit être recherché dans tous les cas.
>
> Lorsque le malade, en état d'exprimer sa volonté, refuse les investigations ou le traitement propose, le médecin doit respecter ce refus aprés avoir informée le malade de ses consequences... (Art 36)[15]

Not only must consent be obtained but the patient also has a right to clear and adequate disclosure of relevant information prior to reaching his decision (Art. 35).[16] The United Kingdom General Medical Council has similarly imposed an obligation on doctors to respect the autonomy of their patients.[17] Doctors who violate these norms are open to disciplinary sanction up to and including the revocation of their licence to practice. We shall see that, in some countries at least, general standards of professional conduct were augmented by specific responses to the spread of AIDS.[18] Both sets of norms had at least as much influence among medical practitioners dealing with the epidemic as the relevant rules of state law. Finally, mention should be made of the Convention on Human Rights and Biomedicine signed in 1997 by most member states of the Council of Europe.[19] The general aim of this Convention is to promote common ethical and legal responses to new and problematic developments in

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Legal Studies 197-215, 209.

[14] For an overview of these structures, cf. A Rogers & D Durand, Bioethics in Europe (Strasbourg: Council of Europe Press 1995) 183-214.

[15] For a short introduction to medical discipline in France, cf. J Penneau, La responsabilité du médécin (2nd ed Paris: Dalloz 1996) 103-113.

[16] It must be said, however, that disclosure may be limited where the patient would otherwise be harmed thereby (Art. 35).

[17] General Medical Council, Serious Communicable Diseases (London: GMC 1997) 3.

[18] For example, cf. General Medical Council, HIV and AIDS (London: GMC 1988).

[19] Among the countries which did not sign were Belgium and Germany. The full text of the Convention can be found at http://www.coe.fr/eng/legaltxt/164e.htm (site visited 17.21, 7/11/00).

medicine such as genetic testing, organ transplantation and embryo research. It too accords central importance to the value of patient autonomy.[20] Article 5 states that

> An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time...

[20] For an overview of the provisions of the Convention, cf. S Oschinsky & Y Oschinsky, 'La convention pour la protection des droits de l'homme et de la dignité de l'être humain à l'égard des applications de la biologie et de la médecine', Journal des Tribunaux 1997, 465-474.

3. AUTONOMY IN AIDS POLICY

a. Threats to Autonomy

In the mid-1980s, opinions varied as to the appropriate public health response to AIDS. Policymakers were reminded in the first instance of the battery of statutory measures, largely carried over from the previous century, which could be deployed to combat the epidemic.[21] These included mass screening of the population, forced testing, isolation and compulsory treatment. All had been used by European states, with varying degrees of success, against the great epidemics of the early industrial era: typhus, small pox, tuberculosis, cholera and so on. In general, the operation of this legislation depended on the judgement of medical experts as to its likely effectiveness. To take one example, in Germany the Imperial Law on Epidemics of 1900 accorded powers of initiation and review to the Imperial Health Office in Berlin.[22] The potential use of medical and state power in this way represented a vivid threat to the autonomy of thousands of individuals, whether infected with HIV or merely suspected of being infected.

As it turned out coercion was chosen in just two jurisdictions in Western Europe: Bavaria and Sweden. In Bavaria the response was based upon three principles of public health: 1) that intervention be as early and intensive as possible; 2) that sources of infection be dealt with without exception; and 3) that all necessary measures be taken to break the chain of infection.[23] Routine compulsory testing was introduced for prostitutes, non-European immigrants and new entrants to the civil service. Gay clubs and saunas were shut down. A system of contact tracing was initiated. Infected persons were barred from certain forms of employment and the uncooperative

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[21] For reviews of such legislation in Belgium, France, Germany, Italy, and Switzerland respectively cf. J-L Denis & F Tulkens, 'Santé publique et droit pénale en Belgique', Revue de science criminelle et de droit penal comparé (1) janv - mars 1996, 1-12; G Giudicelli-Delage, 'Droit à la protection de la santé et droit pénal en France', Revue de science criminelle et de droit penal comparé (1) janv - mars 1996, 13-30; W Loschelder, 'Gesundheitsrechtliche Aspekte des Aids-Problems', Neue Juristische Wochenschrift 1987, 1467-1470; M Gravelli, 'Santé publique et droit pénale en Italie', Revue de science criminelle et de droit penal comparé 1996, 31-49; O Guillod, 'Lutte contre le SIDA: Quel rôle pour le droit pénal?' Schweizerische Zeitschrift für Strafrecht 114 (1997), 130-141.

[22] These powers are now exercised by the Robert-Koch Institut under the Federal Law on Epidemics; for a historical discussion, cf. K Glaser, Vom Reichsgesundheitsrat zum Bundesgesundheitsrat. Ein Betrag zur Geschichte des Deutschen Gesundheitswesens (Stuttgart: Georg Thieme 1960) 1-19.

[23] Cf. P Gauweiler, 'Zur Notwendigkeit eines geschlossenen Gesamtkonzepts staatlicher Massnahme zur Bekämpfung der Weltseuche AIDS', in B Schünemann & G Pfeiffer (eds), Die Rechtsprobleme von AIDS (Baden-Baden: Nomos 1988) 37-60.

could be isolated and detained. Sweden's tradition of paternalist welfarism was reflected in its 1985 decision to include infection with HIV among the venereal diseases covered by the Communicable Diseases Law of 1968.[24] This allowed inter alia for the registration of infected people, contact tracing, and the isolation of patients believed to be behaving in a manner likely to spread the disease. Persons who believe they have been infected and those identified through contact tracing are required to report for testing. Those who are found to be infected must submit to regular medical examination, inform all previous sexual partners and all doctors or dentists by whom they are subsequently treated. The police may be involved in enforcing compliance by recalcitrant patients.[25] Putting these policies in terms of human rights law, it has been noted that they 'involve a massive abridgement of the fundamental right of free movement, the general right of personality and the human dignity of the affected person'.[26]

b. Reflexive Public Health

Across the rest of Western Europe, and since 1989 in Eastern Europe also, the opposite approach has been taken. Instead of coercion, voluntary behavioural change was put at the heart of AIDS policy. This strategy was fundamentally premised upon an instrumentalist understanding of autonomy. Given the highly intimate settings in which the virus is passed from person to person and in the absence of a cure or a vaccine, individuals were encouraged to protect themselves and the wider population. Thus, Catherine Manuel has noted

> L'orientation délibérée vers des attitudes volontaires plutôt que dictées par l'obligation, dans un souci de respecter le choix des personnes, mais aussi de façon à les responsabiliser et à obtenir un changement de leurs habitudes.'[27]

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[24] R Danziger, 'HIV Testing and HIV Prevention in Sweden' (1998) 316 British Medical Journal 293-295.

[25] B Hendriksson & H Yetterberg, 'Sweden: The Power of the Moral(istic) Left', in DL Kirp & R Bayer, AIDS in the Industrialized Democracies: Passions, Politics, Policies (Rutgers University Press: Camden NJ 1992) 315-338, 323ff.

[26] J Hofmann, 'Verfassungs- und verwaltungsrechtliche Probleme der Virus-Erkrankung Aids unter besonderer Berücksichtigung des bayerischen Massnahmenkatalogs', Neue Juristische Wochenschrift 1988, 1486-1494, 1491.

[27] C Manuel et al, 'Les Options de la Politique Française en Matiere de Lutte contre le SIDA', Semaine des Hopîtaux Paris 1994, 843-849, 844 (emphasis added).

Behaviour in the private sphere was to be conditioned by exposure to health education campaigns. These, however tardy and varied in detail, conveyed information on two essential points: the risk of infection and the means of reducing this risk. As Giddens has pointed out, 'in conditions of modernity, for lay actors as well as for experts in specific fields, thinking in terms of risk and risk assessment is a more or less ever-present exercise'.[28] AIDS policy depended, therefore, upon the reflexive incorporation of risk analysis into individual decision-making.[29] To put it another way, the site of disease control had been displaced from an external state-medical authority, to the autonomous subjectivity of affected and at-risk persons.

The public health campaign had more than individual actors as its subjects however. At the outset high risk groups were treated by public health officials and health care planners simply as epidemiological categories. However, some quickly mobilised and were mobilised in the fight against AIDS. In response to lobbying, especially by the gay community, but also by groups of prostitutes and drug users, ministers and health civil servants directed moral and material support towards self-help organisations. This development was, it must be admitted, more typical of some countries, such as Germany,[30] the Netherlands[31] and the United Kingdom,[32] than others. Thus, centralist traditions in France led to a reluctance to devolve policy making and service delivery.[33] In Italy[34] and Spain[35] the preponderance of intravenous drug users

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[28] A Giddens, Modernity and Self-Identity. Self and Society in the Late Modern Age (Cambridge: Polity 1991) 123-124.

[29] For a discussion in relation to public health generally, cf. P Bennett & R Hodgson, 'Psychology and Health Promotion', in R Bunton & G Macdonald, Health Promotion: Disciplines and Diversity (London, New York: Routledge 1992) 23-48.

[30] Cf. M Pollak, 'AIDS in West Germany: Co-ordinating Policy in a Federal System', in BA Misztal & D Moss, Action on AIDS: National Policies in Comparative Perspective (Westport [CT]: Greenwood Press 1990) 121-133.

[31] Cf. JK van Wijngaarden, 'The Netherlands: AIDS in a Consensual Society, in DL Kirp & R Bayer, AIDS in the Industrialized Democracies: Passions, Politics, Policies (Camden [NJ]: Rutgers University Press 1992) 252-280.

[32] Cf. V Berridge, AIDS in the UK. The Making of Policy, 1981-1994 (Oxford: Oxford University Press 1996) c.3.

[33] M Pollak, 'AIDS Policy in France: Biomedical Leadership and Prevention Impotence', in BA Misztal & D Moss, Action on AIDS: National Policies in Comparative Perspective (Westport [CT]: Greenwood Press 1990) 79-100.

[34] D Moss, ' AIDS in Italy: Emergency in Slow Motion', in BA Misztal & D Moss, Action on AIDS: National Policies in Comparative Perspective (Westport [CT]: Greenwood Press 1990) 135-166.

[35] JM de Miguel & D Kirp, 'Spain: An Epidemic of Denial', in DL Kirp & R Bayer, AIDS in the Industrialized Democracies: Passions, Politics, Policies (Camden [NJ]: Rutgers University Press 1992) 168-184.

(less articulate and less well-organised) among the infected population similarly limited voluntaristic strategies. It is nonetheless true that in all countries gay groups played a prominent role in articulating and promoting standards of behaviour in risky situations. In one formulation this 'code of the condom' states that as long as the parties to homosexual intercourse use a condom there is no moral obligation on them to disclose their HIV status and no duty to submit to testing.[36] Adherence to these standards allowed gay men an active role in protecting themselves, as well as enabling the community as a whole to constitute and direct itself normatively. The code involved, in other words, a novel coincidence of individual and group autonomy. This coincidence was endorsed on pragmatic and instrumental grounds by much of the health care establishment. Thus, for example, a cornerstone of Dutch AIDS policy was the belief that:

> Prevention is each individual's responsibility. Only if the norms governing behaviour in the social milieu of the individual supported such change would individuals respond. From this perspective close co-operation with the organisations representing target groups was essential.[37]

Self-regulation and co-operation were only possible, however, where infected persons and members of high-risk groups were free from intrusion, oppression and discrimination.

c. The Role of the Law

It would certainly be wrong to portray the legal response to AIDS as uniform across Europe, even as between those countries which adopted a non-coercive approach. Notwithstanding this, there was an unmistakable tendency among courts, commentators and policy makers to advocate the non-application of repressive infectious disease legislation by doctors and officials, and the application of rules on informed consent, refusal of treatment and confidentiality to the benefit of infected persons and those suspected of being infected. Laws conferring powers were interpreted in a minimalist, doctrines establishing and vindicating rights in a

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[36] DL Chambers, 'Gay Men, AIDS and the Code of the Condom', 29 Harvard Civil Rights - Civil Liberties Law Review 353-410 (1994).

[37] JK van Wijngaarden, 'The Netherlands: AIDS in a Consensual Society, in DL Kirp & R Bayer, AIDS in the Industrialized Democracies: Passions, Politics, Policies (Camden [NJ]: Rutgers University

maximalist fashion. Commentators reconciled autonomy and the public health within the terms of the proportionality test familiar from continental administrative and constitutional law, as well as from the jurisprudence of the European Court of Human Rights.[38] This pattern of analysis allows the several available means to a particular public policy end to be evaluated, compared and ranked in the order in which they burden the rights of affected legal subjects. Although formally a doctrine of public law, we hope to demonstrate that it also structured, even if sometimes only implicitly, the specification of private and criminal law principles in the context of AIDS.

In this context it is most useful to adopt the definition of proportionality applied in Germany. This is because the test has been developed in the case law of the German Federal Constitutional Court explicitly as a means of constraining state-imposed restrictions on the fundamental rights of citizens.[39] It is roughly applied as follows.[40] First, identify the end to be obtained: here slowing the spread of HIV in the population and protecting uninfected individuals. Second, identify the means proposed: here forced and secret testing, isolation and compulsory treatment. Third, ask whether these means are effective, in a basic causative sense, to achieve the end sought. Since coercion tends to drive high risk populations underground and therefore out of reach of social and medical services it is not only likely to be ineffective, it may in fact be counterproductive. Fourth, ask whether there are less burdensome alternatives to the proposed means which would be equally or more effective. In fact it was generally agreed that behavioural change is much more likely if autonomy and privacy are respected and if discrimination is systematically countered.[41] At bottom it is thus clear that the value of autonomy formed an integral part of the legal as well as the policy calculation: to protect autonomy was to protect the public health, to threaten autonomy was to endanger the public health. The

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Press 1992) 252-280, 260.

38 For a range of perspectives, cf. the essays in E Ellis (ed), The Principle of Proportionality in the Laws of Europe (Oxford: Hart 1999).

39 W van Gerven, 'The Effect of Proportionality on the Actions of Member States of the European Community: National Viewpoints from Continental Europe', in E Ellis (ed), The Principle of Proportionality in the Laws of Europe (Oxford: Hart 1999) 37-63, 44-48.

40 Cf. HD Jarass & B Pieroth, Grundgesetz für die Bundesrepublik Deutschland - Kommentar (4th ed. München: CH Beck 1997) 456-459.

41 For a general discussion, cf. K Weare, 'The Contribution of Education to Health Promotion', in R Bunton & G Macdonald, Health Promotion: Disciplines and Diversity (London, New York: Routledge 1992) 66-85.

eminent Australian judge Michael Kirby has called this 'the HIV paradox'.[42] Similarly, the European Court of Human Rights has accepted public health considerations as an important justification for the high degree of protection afforded to the privacy of persons infected with HIV under Article 8 ECHR. It stated that:

> The disclosure of [health data] may dramatically affect [the individual's] private or family life, as well as social and employment situation, by exposing him or her to opprobrium and the risk of ostracism. For this reason it may also discourage persons from seeking diagnosis or treatment and thus undermine any preventive efforts by the community to contain the pandemic.[43]

However, we should note again the precariousness of the particular calculation and the vulnerability of the paradox to empirical dissolution. Both were established at a time when there was no vaccine against HIV and no cure for AIDS, when the progress of the disease in the individual patient was outwith the ken and control of medical science, when prevention was the only policy option and autonomous behaviour modification the only means of prevention. In recent times several of the relevant variables have changed. We shall return to this. It is first necessary to examine briefly the law in Europe as it protects and limits individual autonomy in the context of AIDS.

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[42] M Kirby, 'AIDS and the Law' (1993) Commonwealth Law Bulletin 350-366.

[43] Z v Finland, Judgement of 25 February 1997, Reports of Judgements and Decisions 1997-I 323, 347 (ECtHR).

4. AUTONOMY, AIDS AND THE LAW

a. Testing

The development of an effective HIV test in the mid-1980s lead to the emergence of a distinct set of the legal issues around AIDS. For doctors and public health specialists the test made it possible to determine the modes of transmission of the virus, to distinguish risky from less risky behaviours and to identify carriers. The doctor, thus, became the gatekeeper to the future medical and social status of his patient. Given these consequences and the fact that it could only be carried out on a blood sample, the test implicated the various legal rules on consent and disclosure. The information produced by the test in an individual case could also provide the scientific basis for invoking public law provisions on compulsory detention and treatment.

b. Secret Testing

Most jurisdictions impose criminal and civil sanctions where an individual's rights to physical integrity and self-determination are violated. In the medical context the conduct of therapeutic or diagnostic procedures is generally held to be justified by the consent of the patient thereto; the doctor is correspondingly relieved from civil and criminal responsibility. Legally sufficient consent is obtained where disclosure has been made of the nature of the procedure and the significant risks accompanying it.[44] The standard of disclosure has been defined variously as that which would be required by a reasonable body of medical practitioners, or by a reasonable patient in the position of the actual patient, or by the particular patient in the case.[45] In the context of AIDS, judicial and academic opinion was divided on the question of whether a patient had to give a specific consent to the carrying out of a HIV test above and beyond the consent which he gave to the taking of the necessary blood sample. A minority held that in such cases the patient could be taken as (implicitly) consenting to the conduct of a range of tests, including that for HIV, upon the blood,

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[44] Cf. D Giesen, International Medical Malpractice Law (Tübingen, Dordrecht: JCB Mohr, Martinus Nijhoff 1988) 252-270.

[45] Cf. D Giesen & J Hayes, 'The Patient's Right to Know - A Comparative Analysis' (1992) 21 Anglo-American Law Review 101-122.

at least where a general check-up had been requested.[46] Indeed a doctor who failed to carry out a HIV test, where this was indicated by the risk-profile of the patient, would be failing to comply with the standard of care expected of him in civil law.[47] By contrast the majority held that, given the serious social and psychological consequences of a positive test result for the patient, he and not the doctor should decide on whether it was to be carried out.[48] In essence the requirement of special consent is both inspired by and indicative of 'AIDS exceptionalism'.[49] Diagnosis of HIV status was accordingly to be separated from normal or routine medical practice and a legal duty to seek consent imposed upon doctors. As well as the possible consequences for the patient, public health reasons were adduced in support of the specific consent requirement. Not to have such a rule would either permit or create the suspicion that secret testing was being carried out. At-risk patients would accordingly avoid the medical system making routine care and preventative education almost impossible.

c. Compulsory Testing

The testing of patients against their will is permitted under public health legislation in many European jurisdictions.[50] This has been upheld, in relation to tuberculosis, by the European Commission on Human Rights as a permissible restriction on the right of privacy in certain circumstances.[51] As mentioned above, these powers were relied upon by the Bavarian authorities to introduce compulsory testing of prostitutes, certain classes of immigrant and new entrants to the civil service. Elsewhere forcible testing was rejected in the light of a series of public health considerations.[52] Since

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[46] Cf. J Keown, 'The Ashes of AIDS and the Phoenix of Informed Consent', (1989) 52 Modern Law Review 790-800; E von Hippel, 'Aids als rechtspolitische Herausforderung', Zeitschrift für Rechtspolitik 1987, 123-127.

[47] WH Eberbach, 'Heimliche AIDS-Tests', Neue Juristische Wochenschrift 1987, 1470-1472.

[48] Cf. P Wilson, 'Testing the Boundaries of Consent', (1994) New Law Journal 574, 576; J Langkeit, 'Arztrechtliche Probleme im Zusammenhang mit AIDS-Tests', Jura 1990, 452-460.

[49] R Bayer, 'Public Health Policy and the AIDS Epidemic. An End to HIV Exceptionalism?' (1991) 324 New England Journal of Medicine 1500-1504.

[50] For example, in Germany under §31 I Federal Law on Epidemics; in the United Kingdom under s. 35 Public Health (Control of Diseases) Act 1984; in France under Art. L1 Code de Santé publique (which empowers the Conseil d'Etat to make decrees to this effect after consulation with the Conseil supérieur d'Hygiene publique).

[51] Acmanne v Belgium (1985) 40 Decisions & Reports 251 (ECommHR).

[52] For a thorough discussion with reference to the Bavarian measures, cf. G Frankenberg, AIDS-

HIV antibodies may not be formed for up to six months after infection, a negative test result could not guarantee that the individual concerned was not HIV positive. Indeed such a result might lead to a false sense of security and the adoption or resumption of risky practices. For the extended period in which the patient was infected but asymptomatic there was little that medical science could do for them. Furthermore, the huge cost of systematic and repeated testing would be vastly disproportionate to the remote benefits to be obtained thereby.[53] Finally the probable stigma which would accompany forcible testing would drive those most in need of care and counselling underground. Thus, in France doctors are required to recommend testing to certain categories of patient, but not to impose it upon them.[54] It must be added that in most countries, there is mandatory testing where blood, sperm or organs are to be donated. The data obtained thereby are normally anonymized and do not, therefore, lead to adverse consequences for the person concerned.

d. Detention and Compulsory Treatment

Public health law in most jurisdictions also allows the detention and isolation of persons suffering or suspected to be suffering from infectious diseases in order to prevent the spread of infection.[55] In the United Kingdom AIDS (but not HIV infection) was added to the conditions for which these measures could be taken,[56] but this power was used only once and to so much protest that it is unlikely to be used again.[57] In Germany, by contrast, neither AIDS nor HIV were added to the schedule of infected conditions contained in the Federal Law on Epidemics. Furthermore, only the Bavarian authorities interpreted the Law as conferring upon them the power to

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Bekämpfung im Rechtsstaat: Aufklärung - Zwang - Prävention (Baden-Baden: Nomos 1988) 97-108.

53 For example one study in the United States showed that the cost of finding one infected individual through a pre-marriage screening programme was $715,000, cf. L Gostin & A Ziegler, ' A Review of AIDS-Related Legislative and Regulatory Policy in the United States', 15 Law, Medicine and Health Care 5-16 (1987).

54 In particular to persons about to get married, cf. C Manuel et al, 'Les Options de la Politique Française en Matiere de Lutte contre le SIDA', Semaine des Hopîtaux Paris 1994, 843-849, 848.

55 For example, in Germany under §§36, 37 Federal Law on Epidemics; in the United Kingdom under ss. 37, 38 Public Health (Control of Diseases) Act 1984; in France under Art. L1 Code de Santé publique.

56 Public Health (Infectious Diseases) Regulations 1988.

57 Cf. V Berridge, AIDS in the UK. The Making of Policy, 1981-1994 (Oxford: Oxford University Press 1996) 71.

extend detention and isolation to HIV/ AIDS by analogy.[58] Legal and policy arguments against detention and isolation were explicitly based upon a proportionality analysis: there was little to be gained, having regard especially to the expense involved, from quarantining persons identified as HIV positive when members of the public were best advised to protect themselves by engaging in safer sexual and drug use practices.[59] The issue of compulsory treatment, including vaccination, did not arise because of the inability of medical science to offer affected patients anything more than palliative care. Indeed this lack of an effective therapy bolstered instrumentalist arguments against compulsory testing and detention.[60]

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[58] For the reasoning behind this, cf. P Gauweiler, 'Kasernierung von Aids-kranken Prostituierten?' Zeitschrift für Rechtspolitik 1989, 85-89.

[59] For Germany, cf. M Bruns, 'Nochmals Kasernierung von Aids-kranken Prostituierten', Zeitschrift für Rechtspolitik 1989, 241-244; for the United Kingdom, cf. ED Acheson, 'AIDS: Achallenge for the Public Health' (1988) The Lancet 662-666; for France, cf. Comité Consultatif National d'Ethique pour les Sciences de la Vie et de la Santé (CCNE), Avis sur les Problèmes Ethiques posées par la Lutte contre la Diffusion de l'Infection par le VIH (N° 14) 16th December 1988 = http://www.ccne-ethique.org/francais/start.htm (site accessed 11.17, 7/11/00).

[60] Cf. CCNE, Avis sur les Problèmes Ethiques posées par la Lutte contre la Diffusion de l'Infection par le VIH (N° 14) 16th December 1988 = http://www.ccne-ethique.org/francais/start.htm (site accessed 11.17, 7/11/00).

5. AUTONOMY AND THE FUTURE OF AIDS

a. Medical Advances

The pro-autonomy approach to AIDS, taken by health policy makers, lawyers and judges, was based upon an instrumental concern to deploy the most efficient, least intrusive means of slowing the spread of the virus. As has been shown, the outcome of this proportionality analysis was decisively influenced by the absence of any clinical therapies, i.e. without effective drugs, there was a stark choice between voluntarism and repression. In the last five or six years, however, much improved treatments have been developed and introduced into the care of persons infected with HIV. So-called 'Highly Active Anti-Retroviral Therapy' (HAART), which in fact requires the taking of variable combinations of drugs, dramatically reduces the rate at which the virus is reproduced in a patient's body.[61] It thereby protects their immune system from the perilous deterioration which leads to full-blown AIDS and ultimately to death. This breakthrough has had a revolutionary impact upon the morbidity and mortality of people infected with HIV. Studies in North America have shown a 50-80% decrease in the rates of hospitalisation for people with AIDS, a 50-70% decrease in incidents of major AIDS-related opportunistic infections,[62] and a fall in deaths from AIDS-related illness from 100 per 1000 to 20 per 1000 cases.[63] It has also been shown that HAART reduces the infectiousness of a person who already carries the virus.[64]

More successful still has been the use of Zidovudine (AZT) as a means of reducing peri-natal transmission of HIV. New-born children of HIV positive mothers are now subject to an 8% risk of infection, over three times lower than the risk in 1994.[65]

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[61] JA Cohn 'Recent Advances: HIV Infection—I' (1997) 314 British Medical Journal 487-91; C. Beiser 'Recent Advances: HIV Infection—II' (1997) 314 British Medical Journal 579-83

[62] These figures were reported by the HIV clinics at San Francisco General Hospital and at Johns Hopkins University Hospital, Baltimore, cf. JG Bartlett & RD Moore, 'Improving HIV Therapy', 279/ 1 Scientific American 64, 71 (July 1998).

[63] This change was reported for the period 1994-6 in the province of British Columbia, cf. R Jürgens, 'Background', in R Jürgens (ed), HIV Testing and Confidentiality: Final Report (Canadian HIV/ AIDS Legal Network & Canadian AIDS Society 1999) = http://www.aidslaw.ca/Maincontent/issues/testing/02backgre. html (site accessed 11.33, 16/11/00).

[64] R Royce et al, 'Sexual Transmission of HIV: Current Concepts' (1997) 336 New England Journal of Medicine 1072.

[65] E Connor et al, 'Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment' (1994) 331 New England Journal of Medicine 1173-1180.

These therapeutic advances displace a major assumption of the previous public health consensus: the untreatability of infected and ill persons.[66] They also raise a range of new considerations relating to side-effects, treatment compliance, the development of drug resistance and the abandonment of safe practices. We are forced, therefore, to revisit issues of consent to testing and treatment and to reconsider the well-established primacy of voluntarism in European AIDS policy.[67] We shall see that there are good reasons to fear at least a partial revival of 'traditional' coercive strategies provided for in public health law.[68]

b. Secret Testing

With the advent of new therapies HIV/ AIDS has become a chronic condition, treatable even if not (yet) curable. As a result observers have identified a 're-medicalisation' or 'normalisation' of AIDS.[69] Normalisation can here be understood in two senses: medical and social. First, responses to the disease are increasingly conditioned by a series of medical standards or norms; through this extension of medical knowledge the profession has reasserted control over what had been an area of heightened lay involvement. Second, as a chronic disease AIDS is now a routine, unexceptional part of the social, as well as the medical landscape in Western countries. While much prejudice and discrimination endure, AIDS can no longer be characterised as a crisis or a state of emergency in Europe. Both of these senses of normalisation are significant for the legal issue of whether patients must give specific consent to the testing of their blood for HIV. Since therapies are now available, it can be argued, for example, by a doctor defending a civil action, that the test was medically indicated, that it was in fact a necessary element of providing the patient with adequate care.[70] In ethical terms it could be claimed that the test was carried out

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[66] For a discussion of the shifting categorizations of AIDS, cf. A Clarke, 'What is a Chronic Disease? The Effects of a Re-definition in HIV and AIDS' (1994) 39 Social Science and Medicine 591-597.

[67] This debate has been anticipated in the United States, cf. S Mayer Baker, 'HIV: Reasons to Apply Traditional Methods of Disease Control to the Spread of HIV', 29 Houston Law Review 891-922 (1992).

[68] J-P Moatti & Y Souteyrand, 'Editorial - HIV/ AIDS Social and Behavioural Research: Past Advances and Thoughts about the Future' (2000) 50 Social Science and Medicine 1519-1532, 1526.

[69] KM de Cock & AM Johnson, 'From Exceptionalism to Normalisation: A Reappraisal of Attitudes and Practice around HIV Testing' (1998) 316 British Medical Journal 290-293.

[70] However, the United Kingdom General Medical Council remains faithful to the old approach; cf. C Dyer, 'GP Reprimanded for Testing Patients for HIV without Consent' (2000) 320 British Medical

for the benefit of the patient alone and not simply and solely for the protection of as yet uninfected persons. Expert witnesses will now be available to testify to the orthodoxy of conducting tests on these grounds.

Even more forceful is the argument that, given the social normalisation of AIDS, the consequences of being tested are no longer such as to justify a duty to obtain specific consent. If a positive diagnosis is no longer a 'death sentence' and if earlier conceptions of AIDS as a plague have been marginalised, the patient has (only) as much to fear from testing for HIV as from other, currently routine tests. Finally, we noted that commentators gave much weight to the possibility that people at risk of infection would be driven underground by the fear of secret testing. This consideration may now be less significant given that treatments for AIDS-related illnesses are available where the individual retains contact with the health care system.

c. Compulsory Testing

Under the new therapeutic dispensation, similar arguments may be made in favour of compulsory testing. First, it is again true that such tests would be carried out, at least ostensibly, for the patient's benefit. Second, clinical studies indicate that the sooner HAART is commenced the more likely it is to be effective in prolonging the patient's life and improving its quality.[71] Compulsory testing would accordingly be a way of drawing infected persons into the medical system and subjecting them to a treatment regime. Third, the potential stigma associated with compulsory testing is allegedly diminished by the current construction of AIDS as manageable rather than fatal.

These arguments are, however, less than compelling. Although the cost of the HIV test has fallen, it is still likely that compulsory testing in the form of a widespread screening campaign would be disproportionate to the benefit produced thereby in terms of lives saved and improved. In addition, coercive testing is always likely to be highly stigmatic and politically unacceptable, regardless of the prevailing medical

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Journal 135.

[71] DD Ho, 'Time to Hit HIV, Early and Hard' (1995) 333 New England Journal of Medicine 450-451; S Buchbinder, 'Avoiding Infection after HIV Exposure', 279/ 1 Scientific American 84 (July 1998).

construction of the particular condition. Most significant perhaps is the fact that, notwithstanding the new drugs, the most effective and least costly means of protection against AIDS is still prevention through voluntary behaviour modification. The variety of drug cocktails which make up HAART are very expensive and the regime is frequently difficult to follow. It might be expected, however, that medical professionals, reinstated in a position of authority, would apply techniques of 'soft coercion' in their interactions with individual patients. [72] Such instances of micro-compulsion would not need or even refer to public health law.

Proposals have also been made and implemented, not for general screening, but for the selective testing of members of certain high risk groups without their consent. For example, Professor Michael Closen has argued vociferously that health care workers should be forced to submit to HIV testing as a condition of their employment.[73] In the United Kingdom a doctor was disqualified from practice by the General Medical Council for failing to take an HIV test, in spite of having a strong suspicion that he was infected.[74] Pregnant women in the United States, who are also drug users, have been targeted for compulsory testing in order to enable them to proceed to AZT therapy for the protection of the foetus.[75] In France and the United Kingdom all pregnant women are offered HIV tests at pre-natal clinics as a matter of policy.[76] Furthermore, a British local authority was recently successful in obtaining a court order compelling a HIV-positive mother to allow her newly born baby to be tested for the virus.[77] Both parents were practitioners of complementary medicine and were sceptical of the orthodox biomedical understanding of HIV/ AIDS. The first instance judge completely dismissed this scepticism as unreasonable. A test would be of 'very

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[72] This possibility is canvassed in D Cotton et al, 'HIV Testing Policies for Pregnant Women: A Roundtable Discussion' (1999) AIDS Clinical Care = http://www.accnewsletter.org/feature.asp?strXmlDoc=AC990801&strarticleID=AC199908010110801 (site accessed 16.10, 16/11/00).

[73] ML Closen, 'HIV-AIDS Infected Surgeons and Dentists and the Medical Profession's Betrayal of Its Responsibility to Patients', 41 New York Law School Law Review 57-112 (1996).

[74] C Dyer, 'Doctor who Refused HIV Test is Struck Off Register' (1997) 314 British Medical Journal 845.

[75] Cf. T McGovern, 'Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal and Unsound Approach' 28 Columbia Human Rights Review 469-499 (1997); SC Halem, 'At What Cost? - An Argument against Mandatory AZT Treatment of HIV-Positive Women', 32 Harvard Civil Rights - Civil Liberties Review 491 (1997).

[76] Department of Health. Reducing Mother to Baby Transmission of HIV (London: Stationery Office 1999)

[77] Re C (HIV Test) [1997] 1 Family Law Reports 502 (Wilson J); [1999] 2 Family Law Reports 1004 (CA).

substantial' advantage, as it would allow therapy to commence as soon as possible if the child was found to be infected. The local authority did not seek an order preventing the mother from breast feeding, although commentators have seen this as both desirable and possible under English law.[78]

d. Detention and Compulsory Treatment

It can also be claimed that the variables in the proportionality analysis at the heart of AIDS law and policy have changed as regards the forced detention and treatment of affected patients. Admittedly it is still difficult to defend quarantine and isolation per se. HIV is still transmitted, now as before, largely by intimate means in private circumstances. It is not contagious in the manner, for example, of tuberculosis or cholera. There is, therefore, little to be gained by detaining infected persons against their will when the population as a whole might still be effectively motivated to protect themselves. In addition, if scientific predictions prove correct, HAART will significantly extend the asymptomatic phase of infection. To introduce quarantine in this changed context would be both more burdensome, because of its necessarily longer average duration, and more misleading, in so far as it induced a belief that persons not so detained were free from infection. On the other hand, the very availability of treatment creates a focus for coercion that simply did not exist previously. The possibility of compulsory therapy has also increased due to three further, related factors: the difficulty for the patient in complying with the treatment regime; a perceived increase in unsafe behaviours among members of high risk groups; and the changing profile of the HIV-infected population in Europe.

Combination drug therapy imposes a huge burden upon patients' lives. They are subject to the discipline of taking as much as sixteen pills a day, in various combinations, some before, some after meals. They may suffer serious side effects such as nausea, diarrhoea, fatigue and the uneven spread of body fat.[79] Furthermore, because treatment has to be initiated and followed during the

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[78] A Downie, 'Re C (HIV Test) - The Limits of Parental Autonomy' (2000) 12 Child and Family Law Quarterly 197-202, 202.

[79] MA Chesney et al, 'Adherence to HIV Combination Therapy' (2000) 50 Social Science and Medicine 1599-1605, 1601.

asymptomatic phase, these side effects are often not compensated for by any immediate relief of pain or distress. Each of these factors are generally associated with non-adherence to prescribed therapies.[80] It is no surprise, therefore, to find that American researchers have estimated that up to 50% of treatment failures are due to non-adherence to the HAART programme.[81]

A related issue is raised by the increase in risky behaviours, such as 'barebacking' (i.e. unprotected intercourse between men), which has been the subject of considerable media publicity and academic discussion.[82] The growing willingness to engage in unsafe practices has been related to the arduous and seemingly indefinite nature of HAART, as well as to a sense that after years of precaution and fear, there is now some cause for optimism among affected and at-risk persons.[83] Unsafe practices leading to infection create new risks under the current therapeutic dispensation. In particular re-infection with a different strain of HIV may render the patient's existing course of therapy ineffective. A further consequence, already observed, has been the emergence of drug-resistant strains of the virus.[84]

In addition the demographics of AIDS have changed significantly since the 1980s. Numbers of infected drug users and non-drug using heterosexuals have risen relative to numbers of infected gay men.[85] As we have noted, the gay community in many countries was able to develop an autonomous normative response to the epidemic which partly forestalled any drive to coercion. Both individually and collectively gay men often set the standard for reflexive behaviour modification and the establishment of self-help mechanisms.[86] This capability, it has been claimed, was a contingent product of political coherence, a diverse class background and strong group

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[80] S Mehta et al, 'Potential Factors Affecting Adherence with HIV Therapy' (1997) 11 AIDS 1665-1670.

[81] JG Bartlett & RD Moore, 'Improving HIV Therapy', 279/ 1 Scientific American 64 (July 1998) 71.

[82] M Wells, 'Sex on the Edge', The Guardian, March 14, 2000.

[83] MA Schiltz & T Sandfort, 'HIV-Positive People, Risk and Sexual Behaviour' (2000) 50 Social Science and Medicine 1571-1588

[84] MA Chesney et al, 'Adherence to HIV Combination Therapy' (2000) 50 Social Science and Medicine 1599-1605, 1601.

[85] Relevant statistics, produced by the European Centre for the Epidemiological Monitoring of AIDS, are available at http://www.ceses.org/AidsSurv/ (site accessed 17.05, 16/11/00).

[86] R Rosenbrock et al, 'The Normalization of AIDS in Western European Countries' (2000) 50 Social Science and Medicine 1607-1629, 1616.

solidarity.[87] By contrast drug users are understood by many health care professionals and policy makers to be unable to exercise the same level of control over their behaviour.[88] Homelessness, poverty, general ill health and difficulties with the police, as well as the addiction itself, all militate against successful compliance with complicated medical instructions. A general lack of collective identity and autonomous support structures are seen as having blocked the emergence of group norms concerning safe practices.[89] In this case it may be claimed that the state would be justified in taking paternalistic measures to ensure treatment of such persons where they are infected with HIV.

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[87] D Altman, 'Legitimation through Disaster: AIDS and the Gay Movement', in E Fee & DM Fox (eds.) AIDS: The Burdens of History (Berkeley: University of California, Berkeley Press 1988) 301-315.

[88] R Rosenbrock et al, 'The Normalization of AIDS in Western European Countries' (2000) 50 Social Science and Medicine 1607-1629.

[89] MA Chesney et al, 'Adherence to HIV Combination Therapy' (2000) 50 Social Science and Medicine 1599-1605, 1602.

6. CONCLUSION

In the past epidemics were often met with a coercive response. This history was drawn upon by commentators on AIDS in order to forestall repressive measures. Accordingly, the pragmatic, instrumental elevation of the value of autonomy was bolstered by a subtle message to the effect that changed standards of civility and respect for human rights rendered older approaches socially and morally obsolete.[90] On examination, AIDS policy debates and legal responses to the epidemic, testify to the rise to prominence of individual subjectivity in law and medicine. Especially since the 1960s, the self-governing human subject has become the focus, indeed the supporting pillar of the 'new' public health, of constitutionally guaranteed human rights, and of contemporary medical ethics.[91] Given this, it might be asserted that hithertofore liberal AIDS policies will both endure and will result in a more voluntaristic, less coercive approach to other epidemics too. There are reasons to doubt this, however.

First, where a disease is more contagious and where there is reduced opportunity for self-protection coercion is still justifiable on the proportionality principle outlined above. It would therefore be legally and constitutionally permissible: AIDS exceptionalism is just that. Second, because AIDS was an entirely new epidemic, a decision had to made on whether it should be included in the list of conditions targeted by public health law. By contrast, should other conditions re-emerge, as has been the case with tuberculosis, for example, a raft of repressive measures is already on the statute books ready for use. Third, we would contend, perhaps controversially, that this new subjectivity is not recognised for all persons affected either by AIDS or by other infectious diseases. In medicine, law and ethics, autonomy is accordingly a privilege rather than a right. This contention is borne out when the changing demographics of the AIDS-affected population is considered in conjunction with the new therapeutic possibilities discussed above. In Western societies, AIDS and related conditions, like tuberculosis, increasingly affect the poor, who include the great majority of intravenous drug users. AIDS has also become a disease

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[90] Thus: JM Mann et al, 'Health and Human Rights' (1994) 1 Health and Human Rights 6-23.

[91] For further discussion, cf. J Harrington, 'AIDS, Public Health and the Law - A Case of Structural Coupling?' (1999) 6 European Journal of Health Law 213-234.

predominantly of developing countries. As potential immigrants, the inhabitants of such countries are registered by European authorities and law in terms inter alia of public health risk. We may posit, therefore, an emerging double split in AIDS policy as between rich and poor, and as between domestic and foreign. Both the poor and immigrants are traditionally perceived as irrational and difficult to control. As such they cannot be relied upon to exercise their autonomy in their own best interests or in the interests of society as a whole. Accordingly both have been subject to coercive intervention by the state. The poor, but more especially the peoples of Asia and Africa, have been represented as reservoirs of infection and disease in European culture for centuries. Their status as the bearers of subjective rights is questionable. Given the frequently observed correlation between poverty and ill health including epidemic illness, it is, therefore, hard to argue for a conclusive triumph of autonomy in the realm of public health law.

Arbeitsgruppe Public Health

Public Health ist Theorie und Praxis der auf Gruppen bzw. Bevölkerungen bezogenen Massnahmen und Strategien der Verminderung von Erkrankungs- und Sterbewahrscheinlichkeiten durch Senkung von (pathogenen) Belastungen und Förderung von (salutogenen) Ressourcen. Public Health untersucht und beeinflusst epidemiologisch fassbare Verursachungszusammenhänge und Bewältigungsmöglichkeiten. Solche Interventionen sind sowohl vor als auch nach Eintritt von Erkrankungen bzw. Behinderungen von gesundheitlichem Nutzen. Insofern erstreckt sich der Gegenstandsbereich von Public Health sowohl auf Prävention als auch auf Krankenversorgung. Wissenschaftlich ist Public Health eine Multidisziplin, politisch-praktisch sollen die daraus herleitbaren Wahrnehmungsmuster, Entscheidungskriterien und Handlungspostulate in nahezu alle gesellschaftlichen Gestaltungsbereiche und Politikfelder integriert werden. Im Vergleich zum dominanten Umgang des Medizinsystems mit gesundheitlichen Risiken und Problemen beinhaltet Public Health tiefgreifende Veränderungen der Wahrnehmungs-, Handlungs- und Steuerungslogik für die daran beteiligten Professionen und Institutionen. Die Arbeitsgruppe untersucht fördernde und hemmende Bedingungen für Entstehung, Entwicklung und Wirkungen der mit Public Health intendierten sozialen Innovation.

Unter diesem Gesichtswinkel konzentrieren sich die überwiegend qualitativ ansetzenden und zum Teil international vergleichenden Arbeiten der Gruppe gegenwärtig (1999) auf Prävention und Gesundheitsförderung durch Organisationsentwicklung und Organisationslernen (z. B. in Betrieben und Institutionen), Interventionen in die Lebensweise (an den Beispielen Aids und Ernährung) und Veränderungen im Bereich der Krankenversorgung (an den Beispielen Krankenhaussteuerung und Versorgung von Aids-Patienten).

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