Patrick Kenis, Bernd Marin (Eds.)

Managing AIDS

Organizational Responses in Six European Countries

In the last 15 years, HIV/AIDS has become a challenge for public health, public policy and research. Reducing further HIV transmissions as well reducing the personal and social impact of HIV/AIDS requires a wide range of activities developed by a wide range of organizations – the supply of which varies widely between countries, regions and social groups.

The book describes the programmes which seem particularly effective in dealing with HIV/AIDS and sets out to explain the disparities in their distribution. It documents and tries to understand both similarities as well as the variety of national approaches taken to cope with HIV/AIDS in a number of European countries. On the basis of the *welfare-mix* model, six country studies and an introductory chapter draw particular attention to the different mixes of public policies and private non-profit, community-based activities; the functional mixes between different types of services in the areas of prevention, care, research, control and monitoring, interest representation, fund-raising. The mixes between specialized, so-called "exclusive" HIV/AIDS service organizations and services made available by general, comprehensive, or so-called "inclusive" institutions which provide AIDS-specific programmes among other activities will also be elaborated. The whole range of HIV/AIDS activities, from professional services to self-help, is analysed in a comparative perspective.

The book is based on data from the European Centre / WHO Collaborative Study *Managing AIDS*. It is a comparative policy study focused on the role of non-profit organizations in public health and welfare policy, covering several thousands of organizations and HIV/AIDS programmes in six European countries.

Unexpected similarities and divergence in AIDS service organizations across Europe were found. The sheer multitude of programmes offered called a surprise to experts in the field, as did remaining conspicuous blank spots or deficiencies in services. Degrees of AIDS policy coherence, prevention efforts, service density and quality, self-help and professionalization, medicalization vs. social integration of HIV/AIDS programmes, sectoral specialization and institutionalization all vary tremendously, as do the efficiency and effectiveness of organizational responses to HIV/AIDS. Interestingly, variations in the supply of activities can hardly be explained by epidemiological patterns and corresponding demand and needs.

AIDS management requires long-term institutional strategies and information which cannot be provided by epidemiological or behavioural analysis alone. An effective struggle against HIV/AIDS also requires institution-building, inter-organizational development and policy-field analysis.

With contributions from: Danielle Bütschi, Sandro Cattacin, Hilde Degezelle, Emma Fasolo, Patrick Kenis, Ineke Kester, Bernd Marin, Koen Matthijs, Christiana Nöstlinger, Christine Panchaud, Victor A. Pestoff, Bert de Vroom, Dagmar von Walden Laing, Armand van Wolferen.

Contents

List of Figure	s and Tables	Vii
Preface		xiii
Chapter 1:	Managing AIDS: Analysing the Organizational Responses to HIV/AIDS in European Countries Patrick Kenis / Bernd Marin	1
Chapter 2:	Managing AIDS: The Swiss Case (1983-1992) Danielle Bütschi / Sandro Cattacin / Christine Panchaud	27
Chapter 3:	The Netherlands: The Strong Civil Society Response Ineke Kester / Bert de Vroom / Armand van Wolferen	65
Chapter 4:	The Role of Non-Profit Organizations in Managing HIV/AIDS in Sweden Dagmar van Walden Laing / Victor A. Pestoff	117
Chapter 5:	Managing AIDS in Flanders (Belgium) Koen Matthijs / Hilde Degezelle	171
Chapter 6:	Managing AIDS. Organizational Responses to HIV/AIDS in Austria Patrick Kenis / Christiana Nöstlinger	217
Chapter 7:	Managing AIDS in Italy Emma Fasolo	275
Annexes:		
Annex I:	Reported AIDS Cases in Selected European Countries	321
Annex II:	"Managing AIDS" – The Role of Private Non-profit Institutions in Public Health and Welfare Policy. Original Research Design Bernd Marin / Patrick Kenis	325
Annex III:	European AIDS Service Organizations Inventory Sheet Bernd Marin / Patrick Kenis	345
Annex IV:	"Managing AIDS" Questionnaire Bernd Marin / Patrick Kenis	347
List of Contributors		383

List of Figures and Tables

A) List of	Figures	
Introduction		
Figure 1.1:	Institutional Responses to the Problem of HIV/AIDS	4
Switzerland		
Figure 2.1:	The Development of HIV/AIDS Organizations	
	and Progression of AIDS Cases	31
Figure 2.2:	Development of Public Services and Non-profit Organizations	32
Figure 2.3:	The Development of the National Network	41
The Netherla	ınds	
Figure 3.1:	The Regional Concentration of the AIDS Epidemic	
	in the Netherlands, 1993	72
Figure 3.2: Figure 3.3:	Year HIV/AIDS Activities Began, by Number of Organizations Year HIV/AIDS Activities Began, by Exclusive/Inclusive	91
8	Organization	92
Figure 3.4:	Year AIDS Activities Began, by Organizational Territorial Domain	92
Figure 3.5:	Year HIV/AIDS Activities Began, by Large Cities	94
Sweden		
Figure 4.1:	Number of New AIDS Cases Reported per Year, 1983-1993	127
Figure 4.2:	Number of AIDS Cases Reported 1983-1993 (Cumulative Figures)	127
Figure 4.3:	Number of New HIV-seropositive Cases Reported 1983-1993	129
Figure 4.4:	Year HIV/AIDS Programmes Started	140
Figure 4.5:	Number of HIV/AIDS Cases and Organizational Development,	
	Private Non-profit Organizations 1980-1992	142
Flanders (Be	elgium)	
Figure 5.1:	The Development of New HIV Cases per Three-monthly Term	180
Figure 5.2:	Number of Registered HIV Cases by Gender and Age (1993)	181
Figure 5.3:	Number of Registered HIV-infected Persons by Region (1994)	183
Figure 5.4:	Number of Registered HIV-infected Persons by Provice (1993)	183
Figure 5.5:	Development of AIDS Cases per Semester (1993)	185
Figure 5.6:	Number of AIDS Cases according to Gender, Age Group	
	and Nationality (September 1993)	186
Figure 5.7:	Number of AIDS Cases by Region (September 1993)	186
Figure 5.8:	Number of AIDS Cases by Province (1993)	187
Figure 5.9:	Start of the First HIV/AIDS Activities	
	by Organizational Orientation	191

Figure 5.10:	Start of New Activities Compared to the Development	
	of New HIV/AIDS Cases	192
Figure 5.11:	Structure of the Flemish Organizations by Target Group	198
Figure 5.12:	Organizations by Target Group across the Different Subsectors	204
Austria		
Figure 6.1:	Cumulative Numbers of PWAs and AIDS Deaths (1983-1994)	231
Figure 6.2:	Regional Distribution of AIDS Cases in Austria	
	by Gender (1983-1993)	232
Figure 6.3:	Cumulative Numbers of PWAs by Transmission Group	222
Eigung 6.4.	and Gender (1983-1993)	232
Figure 6.4: Figure 6.5:	Age Structure of Austrian AIDS Cases (1993) Year HIV/AIDS Activities Started	233 242
Figure 6.6:	Year HIV/AIDS Programmes Started by Inclusive/Exclusive	242
rigule 0.0.	Orientation and Reported Number of AIDS Cases	243
Figure 6.7:	Year HIV/AIDS Programmes Started by Legal Status	273
rigure 0.7.	and Number of Reported AIDS Cases	243
Italy	and rannost of Reported The Sources	213
пшу		
Figure 7.1:	Cumulative Number of AIDS Cases and Adjustments	
	for Reporting Delays	280
B) List of	Tables	
Introduction		
Table 1.1:	The AIDS Epidemic and the Organizational Response	
	and Organizational Density in Eight European Countries	11
Table 1.2:	Types of Activities Analysed in the "Managing AIDS" Project	13
Table 1.3:	Percentage of Organizations Providing Specific Types of Activities	14
Table 1.4:	Legal Status of Organizations	15
Table 1.5:	Orientation of Organizations	16
Table 1.6:	National Patterns of Organized Communities and Organized	
	Groups at Risk in Six European Countries	18
Switzerland		
Table 2.1:	AIDS Cases by Target Group and Reported Year	28
Table 2.2:	Percentage of Organizations which Offer	
	HIV/AIDS-related Activities	30
Table 2.3:	Distribution of Organizations by Legal Status	
	and Organizational Orientation	33
Table 2.4:	Number of Activities by Legal Status and Organizational Orientation	34
Table 2.5:	Number of Activities in Local/Cantonal and National Organizations	36
Table 2.6:	Cantonal Measures, Activities and Number	20
T 11 07	of HIV/AIDS Organizations in Each Canton	38
Table 2.7:	The Facets of the Swiss Managing AIDS Model	54

The Netherla	ands	
Table 3.1:	The Development of the HIV/AIDS Epidemic	
	in the Netherlands (1981-1995)	67
Table 3.2:	The Epidemic across Regional Populations (1993)	71
Table 3.3:	Populations at Risk and the Epidemic Load (1993)	75
Table 3.4:	Regulative National Responses to the AIDS Epidemic	80
Table 3.5:	Organizational Density in the HIV/AIDS Policy Domain	83
Table 3.6:	Organizational Response and Organizational Density	
	in the Netherlands, Compared to Other Countries	
	in the European Region (1993)	84
Table 3.7:	Interorganizational Differentiation by Problem Orientation –	
	The Netherlands Compared with Six Other Countries	
	in the European Region (1993)	85
Table 3.8:	The Sectoral and Social Basis of Organizations in the HIV/AIDS	
	Policy Domain – The Netherlands (1993)	87
Table 3.9:	Organizational Differentiation by Target Group Orientation	
	for HIV/AIDS-related Services – The Netherlands (1993)	88
Table 3.10:	Geographical Distribution (Provinces and Some Large Cities)	
	and Organizational Density – The Netherlands (1993)	89
Table 3.11:	Interorganizational Differentiation by Type of Organization	
	and Geographical Orientation – The Netherlands (1993)	90
Table 3.12:	Year HIV/AIDS Activities Began, by Region	93
Table 3.13:	Organizations Providing HIV/AIDS Activities by Subsector	95
Table 3.14:	Managing AIDS in the Netherlands: Datasets	96
Table 3.15:	Organizations Providing HIV/AIDS Activities by Subsector	97
Table 3.16:	Organizations and Specialized Prevention Activities	98
Table 3.17:	Organizations and Care Activities	100
Table 3.18:	Organizations and Their Research Activities	101
Table 3.19:	Organizations and Their Control and Monitoring Activities	102
Table 3.20:	Subsector Activities by Type of Organization	103
Table 3.21:	AIDS Policy Coordination and Implementation Activities	
	by Types of Organizations	104
Table 3.22:	Interest Representation and Self-help Activities	105
Table 3.23:	Organizations and Support Activities	106
Table 3.24:	Organizations and the Number of Paid Personnel	
	for HIV/AIDS Activities	106
Table 3.25:	Organizations and the Number of Volunteers	
	for HIV/AIDS Activities	107
Table 3.26:	Organizations and the Annual Budget for HIV/AIDS Activities	108
Sweden		
Table 4.1:	Government Allocation for the Fight Against AIDS,	
	Fiscal Years 1986/87-1993/94	119

Table 4.2:	Number of AIDS Cases Reported 1983-1993,	
	by Route of Transmission	126
Table 4.3:	Number of HIV-positive Cases Reported 1983-1993	
	by Route of Transmission	128
Table 4.4:	Gender and Number of Heterosexually Transmitted AIDS	
	and HIV-infected Cases Reported 1985-1993	130
Table 4.5:	Number of Organizations by Legal Status and Orientation	131
Table 4.6:	Number of Private Non-profit Organizations	
	by Organizational Structure and Orientation	134
Table 4.7:	Number of Private Non-profit Organizations	
	by Geographical Scope and Orientation	135
Table 4.8:	Number of Private Non-profit Organizations by Membership	
	and Orientation	135
Table 4.9:	Number of Private Non-profit Organizations	
	by Geographical Scope and Membership	135
Table 4.10:	Government Grants to Private Non-profit Organizations	
	for HIV/AIDS Information and Psychosocial Work,	
	1988/89-1992/93	136
Table 4.11:	HIV/AIDS-related Activities per Organization: Range, Median	
	and Mean by Legal Status and Organizational Orientation	138
Table 4.12:	Number of Activities and Expected Frequency by Legal Status	
	and Organizational Orientation	138
Table 4.13:	Number of Organizations Starting HIV/AIDS-related Activities	
	by Period of HIV/AIDS Involvement and Legal Status	140
Table 4.14:	Number of Organizations Starting HIV/AIDS-related Activities	
	by Period of HIV/AIDS Involvement and Organizational Orientation	141
Table 4.15:	Number of Private Non-profit Organizations Involved in HIV/AIDS	
	Activities by Organizational Feature and Orientation	143
Table 4.16:	Number of Organizations Active in Different Subsectors	
	by Legal Status and Organizational Orientation	150
Table 4.17:	Number of Activities in Different Subsectors	
	by Legal Status and Organizational Orientation	151
Table 4.18:	Number of Activities in Different Subsectors Reported in 1992,	
	by Organizational Development	153
Table 4.19:	Number of Separate Information Activities by Legal Status	
	and Organizational Orientation	154
Table 4.20:	Number of Separate Caring Activities by Legal Status	
	and Organizational Orientation	155
Table 4.21:	Number of Separate Caring Activities Reported in 1992,	
	by Organizational Development	156
Table 4.22:	Number of Separate Activities in Policy Coordination & Monitoring	
	and Research by Legal Status and Organizational Orientation	157
Table 4.23:	Number of Separate Interest Representation and Support Activities	
	by Legal Status and Organizational Orientation	158

Flanders (Be	elgium)	
Table 5.1: Table 5.2:	Subsidies for AIDS Prevention Paid by the Flemish Community Number of Registered HIV Cases by Gender	178
	and Route of Transmission (March 1994)	181
Table 5.3:	Number of AIDS Cases by Residential Status and Nationality (1994)	184
Table 5.4:	Mortality by Year of Diagnosis and by the Duration	
	of Observation (December 1993)	187
Table 5.5:	Organizational Response in the Field of HIV/AIDS	188
Table 5.6:	Organizations in the Field of HIV/AIDS by Year of Foundation	189
Table 5.7:	Organizations by the Year in which HIV/AIDS Activities Started	190
Table 5.8.1:	Organizational Responsiveness by Legal Status	
	and Organizational Orientation	194
Table 5.8.2:	Organizational Responsiveness by Legal Status (2)	
	and Organizational Orientation	195
Table 5.9:	Organizational Responsiveness by Province	196
Table 5.10:	Organizations and their Target Groups	197
Table 5.11:	Organizations which Target Those Groups Most Affected with AIDS	199
Table 5.12:	Organizations and Activities across the Different Subsectors	201
Table 5.13:	Organizations by Legal Status across the Different Subsectors	202
Table 5.14:	Organizations by Legal Status (2) across the Different Subsectors	203
Table 5.15:	Organizations by Organizational Orientation	
	across the Different Subsectors	205
Table 5.16:	Organizations by Region across the Different Subsectors	205
Table 5.17:	Number of HIV/AIDS Activities Offered	206
Table 5.18:	Activities Provided by the Organizations by Target Group	208
Austria		
Table 6.1:	Organizational Response to HIV/AIDS in Austria	235
Table 6.2:	Organizational Responsiveness by Legal Status	
	and Organizational Orientation	237
Table 6.3:	Types of Organizations	238
Table 6.4:	Organizations by Target Group	239
Table 6.5:	Organizations by Region and Number of AIDS Cases	240
Table 6.6:	Organizations in the Field of HIV/AIDS by Year of Foundation	241
Table 6.7:	Number of Organizations Active in Different Areas of Activities	245
Table 6.8:	Ten Selected Single HIV/AIDS Activities Offered	254
Italy		
Table 7.1:	Number of Organizations by Legal Status	
	and Organizational Orientation	282
Table 7.2:	Distribution of Organizations by Legal Status	
	and Organizational Orientation	282
Table 7.3:	Number of Organizations by Type of Organization and Legal Status	283

Table 7.4:	Distribution of AIDS Cases by Year and Region	20.4
Table 7.5.	and Rates per 100,000 Inhabitants	284
Table 7.5: Table 7.6:	Number of Organizations by Geographical Area and Legal Status Distribution of Organizations by Region	285
Table 7.7:	Distribution of Organizations by Region Distribution of Organizations by Territorial Domain	286 287
Table 7.7:		201
Table 7.8:	Number of Organizations by Service Access for Clients	288
Table 7.0.	and Legal Status	288
Table 7.9:	Distribution of Service Access for Clients	200
Table 7 10.	by Geographical Location of Organizations	288
Table 7.10:	Number and Percentage Distribution of Activities	20.4
T.1.1. 7.11.	by Subsector and the Organization's Legal Status	294
Table 7.11:	Number and Percentage of Activities by the Organization's	20.4
T-1-1- 7-10	Inclusive/Exclusive Orientation	294
Table 7.12:	Number of Activities in the Area of Prevention	20.5
T 11 7 12	by the Organization's Legal Status	295
Table 7.13:	Percentage Distribution of Activities in the Area of Prevention	20.6
T 11 7 14	by the Organization's Legal Status	296
Table 7.14:	Number and Percentage Distribution of Activities in the Area	205
	of Health Care and Social Services by Legal Status	297
Table 7.15:	Number and Percentage of Activities in the Area of Control	• • • •
	and Monitoring by the Organization's Legal Status	299
Table 7.16:	Number and Percentage of Activities in the Area of Interest	
	Representation by the Organization's Legal Status	301
Table 7.17:	Number and Percentage of Activities in the Area of Prevention	
	by the Organization's Inclusive/Exclusive Orientation	302
Table 7.18:	Number and Percentage of Activities in the Area of Care	
	by the Organization's Inclusive/Exclusive Orientation	303
Table 7.19:	Number and Percentage of Activities in the Area of Control	
	and Monitoring by Inclusive/Exclusive Orientation	304
Table 7.20:	Number and Percentage of Activities in the Area of Interest	
	Representation by Inclusive/Exclusive Orientation	305
Table 7.21:	Number and Percentage of Organizations by Single Activities	
	in the Area of Prevention	306
Table 7.22:	Number and Percentage of Organizations by Single Activities	
	in the Area of Care and Social Services	307
Table 7.23:	Number and Percentage of Organizations by Single Activities	
	in the Area of Control/Monitoring	308