

Professional Activism: AIDS and Civil Society in Sweden, 1982–2000

By Lena Lennerhed and Jens Rydström

Lena Lennerhed is Professor of the History of Ideas at Södertörn University. Her research centres on sexuality, reproduction and medicine in Sweden in the twentieth century. Her latest book is Kvinnotrubbel. Abort i Sverige 1938–1974 (2017).

Jens Rydström is Professor of Gender Studies at Lund University and Docent of History at Stockholm University. His research focuses on the history of sexuality and gender, as well as queer and crip theory. His latest book is Kvinnor, män och alla Andra. En svensk genushistoria (with David Tjeder, 2021).

Abstract

The Swedish HIV/AIDS epidemic accelerated the hybridisation of welfare, as volunteer organisations rapidly professionalised and expanded their welfare services. The media's horror scenarios prompted a sense of urgency which, in turn, motivated politicians and state funding agencies to channel large amounts of money into Swedish volunteer organisations. These included RFSL (the National Union for Sexual Equality), RFSU (the Swedish Association for Sexuality Education) and the Noah's Ark-Red Cross Foundation. The state also worked with the various self-help groups that emerged for HIV-positive drug users, haemophiliacs, and men who had sex with men. This article investigates how these voluntary organisations – old and new – interacted with the state, the public health sector and each other, and how they were changed by professionalisation and hybridisation.

KEYWORDS: HIV/AIDS, Civil Society, Sweden, Activism, Hybridisation

Sweden has a long tradition of popular movements, including trade unions, religious congregations, and the broader sports movement (Lundström and Wijkström 1995). During the 1980s and 1990s, increased government support for the voluntary sector led to its expansion and professionalisation and today, many see the welfare sector as a hybrid between the market, the state, and civil society (Evers 2005, 2008). We argue that Swedish measures to combat AIDS accelerated this hybridisation, mainly as a result of the challenges inherent in reaching out to vulnerable populations. We specifically investigate how the AIDS crisis affected Sweden's existing and emerging voluntary organisations, with special attention to their cooperation and conflicts with each other and the state.

When analysing a complex phenomenon such as the mobilisation against AIDS, it is necessary to use a broad definition of the state. As U.S. political scientists Kimberley J. Morgan and Ann Shola Orloff put it, the state has “many hands,” a metaphor that

highlights the complexity and multiplicity of actors and institutions within the state, pushing us to go beyond reifying simplifications that would view the state as a uniform, cohesive unity (Morgan and Orloff 2017, 18).

Indeed, AIDS activism involved countless negotiations between activists, politicians, and bureaucrats on many levels and in many geographical regions.

Compared to its neighbouring countries, the Swedish response to AIDS was highly centralised and politicised. In 1985, the government established an AIDS Delegation (Aidsdelegation), consisting of representatives from different political parties and answering directly to the Minister of Social Affairs (Thorsén 2013, 100). It maintained a central role until 1992, when it was merged with the National Bacteriological Laboratory (Statens Bakteriologiska Laboratorium) to become the Institute for Public Health (Folkhälsoinstitutet). Since the AIDS Delegation answered directly to the government, shifting political policies had a direct influence on day-to-day decisions in the field. As

opposed to this, the state's most important hands in Denmark and Norway were the Danish National Board of Social Services (Socialstyrelsen) and the Norwegian Directorate of Health (Helsedirektoratet). These non-political agencies worked more independently from the government, with the result that their cooperation with various voluntary organisations was less politicised and conflictual than in Sweden. According to Danish historian Signild Vallgård (2003), Danish authorities tended to define AIDS as a ‘gay disease’. Since attitudes towards gay people were already liberal, so were AIDS politics. Both Denmark and Norway let gay sauna clubs remain open, and Denmark abolished its Venereal Disease Act.¹ Sweden, on the other hand, became known for unusually restrictive measures. Vallgård describes how militarist rhetoric in Sweden combined with an insistence on identifying ‘risk groups’ resulted in a number of coercive measures against HIV-positive people, including a ban on gay saunas and the legal possibility to forcibly isolate people suspected of spreading HIV (Vallgård 2003, 255; Manum 2010; Slagstad 2020). The Swedish state's AIDS policies have been thoroughly investigated by historian of ideas David Thorsén (2013), whereas our study will discuss the voluntary sector.

In this article, we will analyse the activities of older and well-established organisations as well as those that were founded in response to AIDS. Several of the older associations use four-letter acronyms that can be confusingly similar, but we have chosen to keep the Swedish names and the widely used acronyms rather than translating them. In the table below we list all organisations that are mentioned more than once in the text.

Most research on AIDS activism has focused on LGBT organisations, with the notable exception of Virginia Berridge's (1996) early work on British activism and government politics. Sociologist Jeffrey Weeks has argued that government support to AIDS organisations led to an expansion of *all* non-profit organisations. Many of these, he argues, ended up as “service-delivery agencies”, with weakened links to the people they claimed to represent (Weeks 2000, 197). Meanwhile, in Australia, many activist organisations' strong links to

Table 1. Swedish voluntary organisations working with HIV-prevention, 1982–2000

Swedish name	Acronym	Founding year	Name in English	Current name
Convictus		1985	Convictus, support group for former drug users with HIV	Convictus
Förbundet Blödarsjuka i Sverige	FBIS	1964	Association of Haemophiliacs in Sweden	Förbundet Blödarsjuka i Sverige
Kvinnocirkeln i Sverige	KCS	1995	Women's Circle in Sweden	Kvinnocirkeln Sverige
Oasen		1994	The Oasis, support group for HIV-positive immigrants from Africa	Oasen
Positiva Gruppen	PG	1995	The Positive Group in Stockholm, support group for HIV-positive men who have sex with men	Positiva Gruppen
Stiftelsen Noaks Ark/Röda Korset		1987	Noah's Ark/The Red Cross Foundation	Riksförbundet Noaks Ark
Riksförbundet för hjälp åt läkemedelsmissbrukare	RFHL	1965	National Association for Support of Drug Users	Riksförbundet för Rättigheter, Frigörelse, Hälsa och Likabehandling
Riksförbundet för HIV-Positiva	RFHP	1990	National Association for HIV Positive People	HIV-Sverige
Riksförbundet för Sexuellt Likaberättigande	RFSL	1950	National Association for Sexual Equality	Riksförbundet för homosexuellas, bisexuellas, transpersoners, queeras och intersexpersoners rättigheter
Riksförbundet för Sexuell Upplysning	RFSU	1933	Swedish Association for Sexuality Education	Riksförbundet för Sexuell Upplysning

the state raised questions concerning their voluntary work and independence. Also, many associations recruited paid staff among their own volunteers, creating what political scientist Dennis Altman (1994, 103) has described as a new category of professional "Aidsocrats". Several activists have published memory work, documenting the most dramatic years of the epidemic (Svéd

2000; Fouchard et al. 2005; Hansen et al. 2020), while the dynamics of activist alliances have been analysed by British sociologist Margaret Harris and colleagues (2002), who discuss a number of factors that facilitated cooperation and alliance building.

Our study is structured chronologically. First, we discuss the years surrounding the arrival

of the epidemic, when established organisations were forced to reorient their activities and the first self-help groups emerged (1982–1986). Second, we look at a period of organisation-building and conflict. During this time, large amounts of public funding were channelled into the voluntary sector, and different safer-sex messages led to conflict (1987–1990). Our third period is of consolidation and growing cooperation between various HIV-preventive organisations (1991–1995). Our final, fourth period is one of expansion and internationalisation of the organisations' activities (1996–2000).

Our source material consists of written documents, periodical publications, and interviews. Memory interviews demand special methodological attention, since their narratives are filtered through many years of memory processing, but are, nonetheless, invaluable for understanding the larger context and for shedding light on contemporary written sources. The combination of written sources and memory interviews gives a fuller picture of the decisions, processes, and changes that took place during the epidemic, as well as the context necessary to understand them (Abrams 2016).

The arrival of the epidemic, 1982–1986

Sweden's first diagnosed case of AIDS was in 1982 and the first death in 1983. There was widespread fear that the new disease would spread uncontrollably and ignorance about its causes and infection routes contributed to a sense of imminent danger. As we will show in the following, the AIDS crisis forced a number of well-established voluntary organisations to quickly revise their agendas.

Sweden's National Association for Sexual Equality, the RFSL (Riksförbundet för sexuellt likaberättigande, now the Swedish Association for Homosexual, Bisexual, Transgender, Queer and Intersex Rights), was hit hard by the epidemic, as many of its members fell ill and died. It is Sweden's largest national organisation for homo- and bisexual men and women, founded in 1950, and throughout the epidemic its policy was to meet

AIDS with knowledge, community support, and sex-positive messages.

The increase in cases of syphilis and gonorrhoea among homo- and bisexual men during the 1970s had led to increased awareness about health issues within the RFSL. Several of its active members were physicians, who founded the RFSL Physicians' Group already in 1981. This group was active in establishing the gay men's health clinic *Venhälsan* (Venereal Health) at Södersjukhuset Hospital in Stockholm in 1982 and regularly published information about the new disease in the RFSL journal *Kom ut!* (Come Out!). In 1983, before the government had reacted, the RFSL recommended its members to refrain from donating blood (Svéd 2000).

The challenges were many and difficult, and in 1984, RFSL's national chair Hans Ytterberg described in *Kom ut!* how the association's activists were nearing exhaustion. He emphasised how much the organisation had already done in terms of spreading information and encouraging political initiatives. Its members, he warned, could not keep up, not least as all the work was done in their spare time (Ytterberg 1984). Also, the RFSL's relationship with the Swedish National Board of Health and Welfare (Socialstyrelsen) was tense from the beginning. A conflict about the content of one of the RFSL's leaflets funded by the Board increased the tensions, and in 1985, the RFSL decided to leave the Board's advisory group of voluntary organisations since the Board declined to dismiss State Disease Control Physician (Smittskyddsläkare) Per Lundbergh, accused by the RFSL of homophobic and prejudiced statements. Despite these differences, however, 1985 was also the year that the RFSL was granted funding that was to be renewed periodically. This was a historic breakthrough, as the organisation had been petitioning unsuccessfully for public funding since the 1970s (SOU 1984:63, 235). The grant enabled the RFSL to set up the RFSL Counselling Services in Stockholm (RFSL-rådgivningen), later funded by the National Bacteriological Laboratory and Stockholm's County Council (Stockholms Läns Landsting). Similar RFSL Counselling Services were soon set up in Gothenburg and Malmö

and also received regional funding (*Aids-bulletinen* 1986). They were staffed by social workers and pedagogues who were also RFSL members, in accordance with the RFSL's pedagogical conviction that gay men and lesbians, particularly those with a stable and confident homosexual identity, were especially competent when it came to educating and supporting other homosexuals.

Meanwhile, the Aids epidemic brought to the surface internal disagreements in the RFSL concerning gay men's sexuality. In 1984, former RFSL chair Kjell Rindar published a *Kom ut!* article entitled "Safeguard promiscuity". He argued that "gay men today are the group in society that most consistently represents a vital and invigorating sexual diversity. It is necessary that we keep this". He emphasised, moreover, that gay men's "manifold" (mångsamma) sexuality also meant taking responsibility for one's partners, a matter of life and death during the Aids epidemic (Rindar 1984). Other RFSL members disagreed with Rindar's defence of promiscuity. Gay saunas, in particular, were described not only as "commercial plague-spots" (kommersiella pesthärdar), but as inherently socially devastating and an obstacle for gay and lesbian liberation (Engström 1985; Nilsson 1985). This critique, coupled with increased political support for closing saunas, prompted the RFSL to take action. In 1986, it arranged a meeting in Stockholm with gay sauna entrepreneurs, where it was agreed that they would include a condom in the entrance fee and that the RFSL would offer weekly counselling on their premises. Moreover, the sauna owners promised to display information about HIV and AIDS more prominently and refurbish their premises to curb opportunities for anonymous sex (Petersson 1986).

Another existing organisation that had to revise its agenda was the Swedish Association for Sexuality Education, the RFSU (Riksförbundet för sexuell upplysning). Founded in 1933, it promoted a positive approach to sexuality as a source of happiness and well-being, coupled with an ethos of responsibility and awareness of the risk of sexually transmitted diseases and unwanted pregnancies. It would become the largest and most established organisation actively engaged in HIV/

AIDS prevention. Economically, the RFSU was relatively independent, commanding, since the 1930s, an income from the sale of condoms, diaphragms, and other types of contraceptives. These revenues helped finance its activities, including its informative journal *Ottar* (Lennerhed 2002).

Sexually transmitted diseases were one of many priorities for the RFSU, but when the new epidemic grew in force, it was forced to abandon other ongoing campaigns and focus on HIV/AIDS prevention. Over the years to come, it developed and launched new safer-sex campaigns and it also played an important role in collecting and disseminating updated information about the disease. In 1984, *Ottar* published a special issue on seven of the most common sexually transmitted diseases, including AIDS. The new disease was, however, given relatively little space, possibly because not much was known yet. A gay man was interviewed about his fear of the disease, and the reader was introduced to the *Venhälsan* clinic. One of *Venhälsan's* founders, Eric Sandström, criticised the plans to shut down the gay sauna clubs, arguing for their importance as venues for information and contact between men who had sex with men (*Ottar* 1984). Two years later, *Ottar* published another special issue, "Meet AIDS with love, knowledge and condom". Scientists now knew more about the virus, and in this issue *Ottar* provided information that was to be cited and re-used in many contexts in coming years (*Ottar* 1986). Both special issues argued that coercive anti-AIDS methods were inefficient and immoral, and that information, dialogue and safer sex were the best methods to combat the disease.

The RFSU's structure was federative, the national organisation serving as an umbrella organisation for a number of local branches and member organisations. In 1973, the gay and lesbian association RFSL had joined the RFSU as a very active member. The RFSL was unanimously welcomed and during the first years all its proposals were carried. This changed in the 1980s, however, when a number of conflicts arose between the two organisations. At the RFSU's 1984 annual general meeting, RFSL representatives tried to block the re-election of a board member, a psychiatrist

and long-term RFSU activist who had expressed doubts about adoption rights for same-sex couples. This caused a heated debate, but the psychiatrist was re-elected despite RFSL's protests.² A crisis of confidence thus emerged between the RFSL and the RFSU already at the onset of the AIDS epidemic, but this did not seem to effect grass-root level cooperation. In 1983, the RFSU launched a summer campaign called the Love Buses (*Kärleksbussarna*), a number of Volkswagen campers deployed to beaches and camping grounds in order to spread RFSU sex education messages to areas where the organisation did not have local branches. The Love Buses became a familiar sight in Swedish summer resorts for more than two decades and soon focused almost entirely on AIDS and safer-sex information. From 1987 they were funded by the AIDS Delegation and from 1992 by its successor, the Institute for Popular Health. Over the years, the Love Buses contributed to increased cooperation between the RFSL and the RFSU and to increased contacts between their activists. They were followed by a joint RFSU/RFSL campaign, "Love Power", which was specifically aimed at young adults.³

Like gay men, haemophiliacs were also hit hard by the epidemic and also had an organisation that had to face new challenges. Out of Sweden's ca. 600 haemophiliacs, one out of six was infected with HIV via blood factor medication in 1985. About twenty per cent of these were children – the first one to die of AIDS in this group was a nine-year-old boy. Five women acquired the virus from male partners, in some cases because their doctors had not warned them that HIV was sexually transmitted (Karlsson 2005, 6, 41; Sjöblom 1985; Öhman 1985). The Association of Haemophiliacs in Sweden (*Förbundet Blödarsjuka i Sverige*, FBIS) had been founded in 1964 and organised haemophiliacs, their families, and health care professionals. In the 1980s, Swedish care for haemophiliacs had earned a good international reputation and involved close cooperation between researchers, practitioners, and patients. The wave of HIV infections, however, led to a massive crisis of trust between patients and caregivers (Karlsson 2005). Moreover, the FBIS reacted to the first years of AIDS

with a culture of silence. Its membership publication *Journalen* (The Journal) emphasised that one must speak not of haemophiliacs as a risk group, but of people contaminated by blood (*blod-smittade*), and it argued that "discretion and consideration" was the best way to support those who had contracted the virus (Palmlad and Söderlind 1986). FBIS board member Gösta Knutsson also insisted on discretion: "It is important, not least for our children and young adults with haemophilia, that we do not establish a linkage between haemophilia and AIDS" (Knutsson 1986).

Intravenous drug users were a third group whose support organisation had to cope with a radically new situation. The RFHL, Sweden's National Association in Support of Drug Users (*Riksförbundet för hjälp åt läkemedelsmissbrukare*) was founded in 1965 and organised both former drug users and progressive social workers. It had developed exit programmes based on voluntary abstinence from drugs, coupled with intensive peer support from former drug addicts, and had a comparatively solid financial position thanks to funding granted its so-called treatment homes (*behandlingshem*). These were generally co-funded by local governments, also receiving support from the National Board of Health and Welfare (Adamson 2004).

In January 1984, Margareta Böttiger from the National Bacteriological Laboratory gave an interview in RFHL's membership publication *Slå Tillbaka!* (Strike Back!). Böttiger reported on the high incidence of AIDS among drug users in the United States and said that it was assumed that an unknown virus spread through sharing infected syringes (Heijbel 1984). Since the Laboratory had limited expertise on drug use, RFHL activist Claes Heijbel invited Böttiger to meet with a group of active drug users. They demonstrated how they injected the drugs and gave information on their needle-sharing habits. The Laboratory paid participants 500 crowns each, for, as Heijbel put it, "Otherwise they would have had to work, so to say, to maintain their abuse – and they had a knowledge that was lacking in the world of disease control." Here, Heijbel referred to the illegal activities that many drug users were engaged in to finance their drug use (Heijbel, interview 2020).

In May 1986, the RFHL initiated its HIV project, directed towards drug users with HIV. *Slå Tillbaka!* announced it as “one of the activities that have been initiated with money from the thick wallet of the Ministry of Social Affairs” (Bengtsson 1987). This allowed the RFHL to meet with other organisations working with HIV prevention and learn more about HIV, which was especially important, as many treatment homes were reluctant to accept people with HIV (Heijbel 1985). As former RFHL chair Sven-Åke Lindgren explained:

There was quite a lot of prejudice on both sides, so to say. Prejudice from drug addicts and treatment staff towards homosexuals and their organisations, and also the other way around, towards drug addicts and prostituted women who were on heroin (Lindgren, interview 2020).

Thus, during the first two years of the pandemic, those organisations that became engaged in HIV-prevention were already existing organisations that worked in the interest of their members or, in the case of RFSU, had a broader agenda concerning sexual and reproductive health and rights. But soon there was a growing demand for peer-support groups organised by HIV-positive people themselves. The first self-help group for people living with HIV was founded in November 1985, when two friends and former drug users, who had recently tested positive for HIV, Tomas Sandberg (later Moberg) and Robert Pettersson (later Högström) formed a network for people in the same situation: the Convictus.⁴ They met once a week and initially focused on peer support, but in April 1986 the Convictus had its first formal annual meeting.⁵ During the first year, it received invaluable support from the RFHL’s HIV project (which ran from 1986 to 1989), but its members lacked experience in organisational and grant-application work. Tomas Sandberg complained in Convictus’ first Annual Report:

We spent a lot of time writing applications and petitioning people with power in different local agencies. All of them patted us on our

*heads and thought we were doing a great job but could not help us.*⁶

In spite of this, Convictus’ level of activity was impressive. At this point, Sandberg and Pettersson were the sole HIV-positive former drug users willing to give public talks and they were frequently invited to schools and care facilities to educate staff and students. They also visited prisoners with HIV and developed an ongoing cooperation with the Österåker correctional facility.⁷

Just as Convictus had been formed by members of the RFHL and received both moral and economic support from the larger organisation, a number of RFSL members founded, in December 1985, Sweden’s first self-help group for HIV-positive men who had sex with men. The Positive Group in Stockholm (Positiva Gruppen or PG) was inspired by the English organisation Body Positive, and several PG members attended one of Body Positive’s courses in London. Anonymity was important for PG and, in order to protect the anonymity of its members, PG’s first chair, former RFSL chair Kjell Rindar, did not carry the virus himself – a point of some importance, as we shall see below.⁸

Convictus and PG were both grassroot, bottom-up organisations, initiated by HIV-positive gay men and former drug users. By contrast, the Association Noaks Ark (Noah’s Ark) was an organisation formed by allies, but one that reached out to members of all risk groups. It was founded in 1986 by the openly gay doctor Jan-Olof Morfeldt, and several of its members were also active in the RFSL’s Physicians’ Group, the *Venhälsan* Clinic, or the Association of Doctors Against Aids. It was to become one of the most influential anti-AIDS organisations in the country.

Organisation-building and conflict, 1987–1990

After the first years of fear and anxiety, most support organisations achieved relative stability. Central and local government bodies channelled money to them, making it possible to hire staff and

expand activities. This was also the period when the Swedish Government banned gay saunas and amended the Law on Contagious Diseases to allow for forced isolation of people deemed at risk for spreading HIV (Thorsén 2013, 116, 206).

For the gay and lesbian organisation RFSL, the AIDS epidemic initiated a period of rapid expansion. It lost the political battle to save the gay saunas, which were outlawed and closed in 1987 (Thorsén 2013, 206). In terms of income and membership, however, the gay and lesbian organisation thrived. In 1988, it opened new premises in central Stockholm, the House on Sveavägen (usually known as the House), whose many floors afforded space for many different activities (RFSL 1988; Ahlberg 2000). Most of the House's funding came from the City of Stockholm, with additional contributions from Stockholm's County Council and some central government agencies (Skagert 1987; Petersson and Svéd 2018). Although the publicly funded House was a step forward for the RFSL, it came at a cost. Some members said they missed the old community centre's homely atmosphere (Thorsén 2013, 214) and the House's central, highly visible location could also be a problem. RFSL counsellor Ann Colleen told us that some people did not dare to come to the House's Counselling Service for fear of being seen. It had been easier to guarantee anonymity in the old offices (Colleen, interview 2018).

The House represented progress, openness, and visibility, but also fuelled discussions about the RFSL's independence and self-determination. David Thorsén has described the RFSL's position as complex. During the 1980s, it assumed an increasingly activist role – while also becoming entrenched in a broader societal AIDS establishment (Thorsén 2013, 216). For instance, the RFSL fiercely criticised the Swedish state, accusing politicians of doing too little, too late, and it repeatedly demanded more influence on decision-making. Meanwhile, however, it participated in various state agencies' advisory groups and cooperated with the National Board of Health and Welfare in launching information campaigns.

Lesbian members proved a further source of tension within the RFSL. Their role had been a

matter of discussion since the 1950s, but the increased focus on men and men's sexuality inherent in AIDS prevention made the issue still more difficult to handle. In 1988, several women left the RFSL to found the association Lesbisk NU (Lesbian NOW), while the lesbians who remained in the RFSL demanded greater space for developing lesbian identity and culture within the organisation. This, they argued must be possible to combine with the solidarity work done with gay men with AIDS (Esgard 1986; Rydström 2011, 193).

The larger sex-reform organisation RFSU remained the RFSL's most important political ally in its HIV/AIDS prevention efforts. For example, the RFSU joined the RFSL in criticising the state's coercive measures, and wholeheartedly supported its demand that the state provide anonymous HIV-testing. Differences arose, however, on the definition of safer sex, since the RFSU did not agree with the gay and lesbian organisation's position that unprotected oral sex was 'safe enough', as long as no sperm was swallowed.⁹ Generally, the RFSU kept up better relations with central and local government agencies than did the RFSL. Although the RFSU repeatedly criticised the state's coercive measures, it maintained its dialogue with state decision makers.

The epidemic also led to tensions within the National Association in Support of Drug Users, the RFHL. When its members became aware of that infected syringes could spread a deadly disease, they had to initiate a painful internal discussion about methadone treatments and syringe-exchange programmes. The Association had long opposed both these practices, being deeply committed to the belief that the only way a person could stop abusing drugs was through total abstinence and peer support. To administer methadone or clean syringes to intravenous drug users, they argued, represented a kind of 'treatment pessimism' – that was, to label a heroine user a distinct type of person, forever and incurably a slave to addiction (Nilsson 1987). Since HIV almost invariably led to a certain death, however, many of its members thought it was time to reconsider, but they had to work hard to convince the majority. The stiffest resistance to change

came from the social workers that were active in the RFHL, which led to increased internal tensions as former drug users began to feel a division between 'us' and 'them' (Heijbel 1987). In 1988, a stormy Annual General Meeting debate almost tore the RFHL apart. Finally, consensus was reached that the association would accept but never "actively engage in" methadone programmes, while continuing to fight "the myth of incurability" (RFHL 1989, 20).¹⁰

The only organisation that had the explicit ambition to reach out in support to all people with HIV, regardless of how they had been infected, was the Noaks Ark. Its instigator Jan-Olof Morfeldt began cooperating with one of the oldest organisations in the voluntary sector, the Swedish Red Cross (Röda Korset), which in 1987 resulted in the Foundation Noaks Ark/Röda Korset. Morfeldt was elected chair and the King's sister, Princess Christina, agreed to serve as the new organisation's vice chair. The Foundation rapidly became one of Sweden's wealthiest and most influential HIV-support groups. Its statutes named its purpose as working "for the limitation of the HIV epidemic and its consequences" within the context of human love and compassion, supporting the sick and infected and their loved ones, fighting ignorance and prejudice, and, finally, providing a guesthouse and courses for volunteers.¹¹

The Noaks Ark/Röda Korset Foundation was solidly financed from its inception. In 1987 and 1988, the Ministry of Social Affairs, the City of Stockholm and Stockholm's County Council contributed more than 10 million crowns (approximately one million Euro) to the Foundation; meanwhile, the Swedish Red Cross granted a little over 2.5 million. In addition to this, it received more than two million crowns in other donations.¹² As an independent foundation, it had full autonomy, and could choose its own HIV-preventive messages and policies (Johansson 1997, 34). In a 1999 interview, Morfeldt emphasised the importance of maintaining control over the information put out, since only facts could combat false rumours and diverging safe-sex messages. "And there are many such tendencies that we have met over the years. We did not open up to become a large

membership-based organisation" (Olsson 1999, 88). Education remained a key part of Noaks Ark/Röda Korset's activities. The Foundation offered courses to its own volunteers, family members of HIV-positive people, and key persons within the Swedish Red Cross. It also offered educational programmes to the public, including the Swedish Association of Municipalities (Svenska Kommunförbundet) and the Municipal Home Care Services (hemtjänst) in the larger cities. Finally, its AIDS Helpline, staffed by paid employees, received calls from all over the country – more than 12,000 in 1988.¹³

Noaks Ark/Röda Korset developed into a non-profit organisation with hundreds of volunteers, a largely apolitical, knowledge-based organisation. Its building in central Stockholm, known as the Ark (Arken), housed a broad variety of activities, with a café, a library, group rooms for discussions, assembly halls for seminars and lectures, administrative offices, the AIDS Helpline and a guesthouse where the sick and their families could stay. The single largest group of people with HIV or AIDS to contact Noaks Ark were gay men. They were also in majority at the guesthouse, but its facilities were used by former drug users and by a network of straight men and women with HIV as well. The Foundation Noaks Ark/Röda Korset established contacts with refugee centres and immigrants' associations, such as the African cultural groups EDO and the African Council in Sweden. It also created a network for Spanish-speaking, HIV-positive people residing in Sweden, and its financial resources allowed it to provide economic support to HIV wards in three of Stockholm's hospitals, in order to increase the patients' comfort and wellbeing.

The founding of a number of Noaks Ark local branches raised the question of national organisation. In autumn 1987, representatives of five Noaks Ark branches – Stockholm, Gothenburg, Malmö, Karlstad, and Visby – met in a conference facility north of Stockholm to discuss the formation of a national umbrella organisation. However, when Noaks Ark Stockholm sent out a bylaws proposal, several branches protested against its centralist structure. In response, a January 1988 meeting in

Stockholm agreed that the Ark would be headed by a national board, consisting of chairs from each branch, complemented by national-level groups coordinating Noaks Ark's work of support, education, and information. The national board was to mediate in conflicts within the local branches and all branches were to adopt the Noaks Ark template bylaws (normalstadgar). In particular, they were to endorse the two opening articles, which defined the principles guiding the association's activities. Noaks Ark Gothenburg was absent from this second meeting, but instead Noaks Ark Östergötland had joined.¹⁴ Indeed, Noaks Ark Gothenburg collapsed in 1990, after intense infighting.¹⁵ Nonetheless, Noaks Ark activities continued to expand nationally and a few years later, the annual report of Noaks Ark Malmöhus listed eight branches across the country.¹⁶ The origin and activities of each branch differed according to the local AIDS situation. In the big cities, Swedish-born gay and bisexual men dominated. The large refugee facilities in and around Växjö resulted in the Noaks Ark Kronoberg primarily directing their support towards heterosexual immigrants, who had been infected in their home countries (Khaghani, interview 2022).

One group that was more reluctant to connect with the others were the haemophiliacs. As pointed out above, haemophiliacs with HIV had difficulty in finding counselling and support, even if the FBIS policy of "discretion" was challenged towards the end of the 1980s. FBIS member Martin Jakobsson (pseudonym) told us in an interview that as a haemophiliac, he was practically born into the organisation, but he had not been very active before 1986, when he was 23 years old and tested positive for HIV. He then turned to FBIS for support but found none. Indeed, he told us, FBIS did very little for members with HIV.

FBIS was a small organisation with rather scarce resources, and everything was a mess. The chair, Raoul Bolinder, did his best, I guess, but it was difficult. FBIS never arranged any activities specifically aimed at those of us who had contracted the disease (Jakobsson, interview 2020).

HIV-positive haemophiliacs turned, instead, to the Noaks Ark. Starting in 1987, Noaks Ark organised psychosocial therapy for haemophiliacs with HIV and their families. In January 1988, it arranged a meeting with the recently founded group Unga Blödarsjuka (Young Haemophiliacs), assembling about twenty young HIV-positive haemophiliacs for group discussions, a lecture on sexuality, and a meeting with gay fashion designer Sighsten Herrgård – the first person who came out as HIV positive in Sweden (FBIS kamratstöd 1988).

While HIV-positive haemophiliacs struggled for visibility and support, Convictus continued its activities in support of HIV-positive former drug users. After a difficult first year, its activities and membership levels stabilised. In the autumn of 1988, Convictus founders Tomas Sandberg and Robert Högström appeared in a documentary by Torsten Letser entitled *Dödspolare* (Pals until Death). They described love, sex, and life for those living with HIV in a prejudiced society, emphasising that neither drug addicts nor people with HIV should be seen as dangers to others. "Yes, we're actually ordinary people", as Tomas put it. "I wish all those who are currently afraid of us who are infected could get that into their heads" (Letser 1988).

During this period, Convictus formalised its cooperation with the Färingsö women's prison and started a women's group.¹⁷ By 1988, Convictus had been awarded generous public funding and could open its own community centre in central Stockholm. The scope of its activities was also affected by Sweden's increasingly restrictive drug legislation (possession and use of drugs were criminalised in 1988), which also meant that more state money was invested in addiction treatment and the general prevention of drug abuse (Tops 2001). The state willingly provided funding for HIV-prevention among drug users, in fear of an explosion of illness. There was no such explosion, however, since Swedish drug users refrained from sharing syringes with HIV-positive people (Nilsson 1988). Indeed, many of the resources allocated for drug users with HIV were never spent, and the eight-bed ward for drug users with AIDS that opened in 1990 was closed already in 1992.¹⁸

Like *Convictus*, so did the Positive Group in Stockholm experience a period of growth. As it ruefully noted in its 1989 annual report, "It is of course with mixed feelings that we see that the membership of the Positive Group is growing so fast".¹⁹ During its first years, PG members concentrated on mutual support, not least in supplying adequate information. The PG soon engaged, however, in work to improve the rights of people with HIV, emphasising the links between social, psychosocial, and political activities. Despite various sources of funding – from the National Board of Health and Welfare, Stockholm's County Council, the RFSL's Aids Fund, and Noaks Ark/Röda Korset – it was not a wealthy organisation. It was, further, like *Convictus*, vulnerable to activists' falling ill and dying. On the other hand, PG members often had extended international networks. In 1989, PG participated in a National Lesbian and Gay Health Conference in San Francisco, an International AIDS Conference in Montreal, and an international conference for people living with HIV held in Copenhagen. In Sweden, it was represented in the AIDS Delegation's advisory group for voluntary organisations, where it met with other groups involved in preventing HIV. It arranged a summer camp for 36 members living with HIV and staged a demonstration outside the American Embassy in Stockholm to protest U.S. immigration policies that prohibited the entry of foreign citizens with HIV.²⁰

Funding from Stockholm's County Council made possible a half-time staff position in 1990 and later that year, a grant from Stockholm City allowed the PG to move into its own premises.²¹ Five years after its founding, the Positive Group in Stockholm had become a well-established support group with a growing number of members (around 600 in 1990). It could now also mount critiques of close allies such as the RFSL and the Noaks Ark/Röda Korset. Minutes from the PG Ideological Working Group (*Idépolitiska gruppen*) complain that Noaks Ark was too irresolute vis-à-vis government agencies and that the RFSL lacked the mandate to speak for gay men who were HIV-positive. The RFSL was certainly well-meaning, as the Group put it, but "are people

with HIV represented in the board of RFSL? /.../ Do they know what it is like to live with HIV?"²² In the experience of the working group's members, other organisations often ignored people living with HIV. Because of this, "it is actually we [the PG] who openly represent gay men with HIV".²³ The minutes do not tell whether these points of view were communicated to either the RFSL or Noaks Ark/Röda Korset, but the PG continued to cooperate with both.

PG discussions often focused on the HIV-positive person's right to love and sex. "When will someone tell everyone that safe sex makes it possible to have a sexual relation with a person with HIV without being infected?" the PG Annual Report asked. But the PG also criticised the discriminatory practices of many gay men. It strongly condemned requests in gay-publication contact ads such as "it goes without saying that you are tested and HIV-negative" as unnecessarily stigmatising.²⁴ The group further emphasised the right of HIV-positive people to sex. An editorial in its publication *T-Cellen* (The T-Cell) entitled "Love, Sex, and HIV" ended with the words "Fuck each other into oblivion – with a condom" (Heidkamp 1996).

By 1990, different peer-support group for people with HIV organised nationally. That January saw the founding of the National Union for HIV Positive People (*Riksförbundet för Hivpositiva*, RFHP, later HIV-Sverige). It was meant to be an umbrella organisation for HIV-positive persons' networks and peer-support groups, formed because HIV-positive people were subject to "discrimination, injustice, and many kinds of human-rights violations in society".²⁵ Its meetings were attended by representatives of Sweden's other HIV-positive support groups. During its first year, the RFHP gained financial support from the state's National Board Health and Welfare; after that, from the AIDS Delegation and Institute for Public Health. RFHP described itself as a patients' organisation, complementing government agencies' HIV information campaigns. It worked for the rights of people living with HIV, insisting that their voice be heard in all decisions affecting them.²⁶

Consolidation and cooperation, 1991–1995

Almost a decade after the first AIDS-related death in Sweden, most voluntary organisations working with HIV prevention had become well-functioning, semi-professional units, heavily dependent on public funding and using short-term staff, hired for a specific project. Death tolls in Sweden were still high, but the spread of the infection had levelled out and the public's general fear had abated.

This was also the period when *Convictus* underwent important changes. Over time it had become clear that the double stigma that HIV-positive former drug users experienced was a heavy burden to carry. In spite of good funding and good relations with the authorities, *Convictus* remained a vulnerable group. Not only did its members fall ill and die, as it happened in all HIV-positive peer support groups, but they were also battling a history of drug abuse and the difficult recovery from drug dependency. After some of its key activists had suffered relapses into drug abuse in 1993, the organisation was restructured. It was now run, not by formerly drug-using HIV-positive persons, but by allied activists who were neither HIV-positive nor former drug users.²⁷ The umbrella organisation for HIV-positive people, the RFHP, however, had a strict policy regarding who had the right to speak for people living with HIV and refused to accredit *Convictus* representatives who were HIV-negative. As a result, *Convictus* lacked representation in the RFHP for several years.²⁸

Contacts and networking were an important part of the RFHP's activities. In its capacity of national organisation for people living with HIV, it networked with state-run clinics, politicians, and government agencies, as well as with voluntary organisations such as the RFSL, the RFSU and the Noaks Ark/Röda Korset. It also established ties to Nordall, the Nordic cooperation network for HIV organisations, and with its European counterpart EuroCaso. Some of the RFHP member groups were relatively stable, while others were more ephemeral, sometimes with only handfuls of members. Its most influential members remained the self-help groups for people living with HIV, such as the

Positive Group branches in Stockholm, Malmö, and Gothenburg, while many other organisations that joined the RFHP vanished rather quickly.²⁹

There was an important difference between Stockholm's self-help groups and groups in other parts of the country. Stockholm was big enough to host specialised organisations for HIV-positive people: one for men who had sex with men, one for former drug users, one for haemophiliacs and one for those who had been infected heterosexually. PG Stockholm, for instance, was founded by RFSL members and only organised men who had sex with men, while it was left to *Convictus* and FBIS to take care of former drug users and haemophiliacs, respectively. By contrast, PG Väst had its roots in Gothenburg's City Mission and PG Syd derived from Noaks Ark Malmöhus. Both of these organised HIV-positive people regardless of how they had been infected.

Thus, long-established groups, such as the RFSU, the RFSL, the RFHL, and the haemophiliacs' organisation FBIS, dominated the field in the 1990s together with a number of new, successful groups such as Noaks Ark/Röda Korset, the various Positive Groups and *Convictus*. Other groups were small and ephemeral. Two are worth mentioning, however, since they represent telling absences among Sweden's HIV-preventive groups: a Swedish ActUP initiative and a sex-worker organisation. While ActUP was crucial for militant AIDS activism in countries like France and the United States, its Swedish counterpart was a one-man operation, run with the help of a handful of sympathisers and allied activists. ActUP Stockholm was founded in February 1990, when gay activist Janne Paasio and friends protested against insulting AIDS jokes in the *Nordiska Museet Yearbook*. The group's most spectacular and probably sole public protest occurred in February of 1991, when its members blocked access to the premises of the government's AIDS Delegation, demanding the resignation of state Disease Control Physician Per Lundbergh, who had raided the *Venhälsan* Aids clinic ordering the seizure of the journals of 14 patients suspected of spreading the disease. This protest seems, however, to have been ActUP Stockholm's last public manifestation. Janne

Paasio moved to Berlin and died there in 2000 (Reporter 1990; Haverdahl 1991; Paasio 2015).

In many countries, sex-worker organisations worked with HIV prevention, as in neighbouring Norway, where the Prostitutes' Interest Organisation PION (Prostituertes Interesse-Organisasjon i Norge) was founded in 1990 in order to spread information about HIV among streetwalkers. It received government funding from the start and is still organising sex workers and their allies in Norway (Rydström 2021). Such mobilisation was strikingly absent in Sweden, where a strong emphasis on zero-tolerance policies has characterised all government initiatives on sex work and drug use since the 1980s. This, combined with a strong radical-feminist influence on Swedish women's movements led to a lack of interest in a sex-workers' rights approach. A sex-workers' association had been founded already in 1977 but was dormant when the AIDS epidemic broke out. In the spring of 1991, however, a group of Stockholm streetwalkers met in Noaks Ark's premises to form the group Valkyria. In October 1991, its members participated in an international sex-workers' conference in Frankfurt, where they also met representatives of the Norwegian organisation, and in 1993, Valkyria petitioned the Minister of Social Affairs. The group's main focus was on sex workers' rights, however, and information and support concerning HIV was only part of its objectives. Due to internal conflict and negative reactions from the surrounding society it ceased to exist already in 1995 (Rydström 2021).

A number of factors in Swedish society can explain the absence of a militant AIDS activist group like ActUP, and of an active sex workers' association. ActUP was less necessary in Sweden than in, say, the US, due to Sweden's well-developed health-care system and a long tradition of public sex education. Moreover, state emphasis on zero-tolerance politics, combined with feminist mobilisation against prostitution since the late 1970s are factors that have made it next to impossible to create and consolidate a sex-workers' rights movement (Rydström 2021).

While gay men and former drug users with HIV had organised early, there was a number of

significant latecomers, most importantly women and immigrants, who organised only in the mid 1990s. In 1995, the Women's Circle in Sweden (Kvinnocirkeln i Sverige, KCS) was founded in Malmö. In cooperation with RFSU's Malmö branch, the new organisation arranged a first meeting for HIV-positive women in 1996 to discuss how they were affected by HIV (Brander, interview 2020). For the most part, HIV-positive women had been infected through heterosexual contacts or intravenous drug use, while a small number had contracted HIV through blood products (Oförändrat 1996). The Women's Circle sought to publicise the needs and health problems specific to women living with HIV, and a high priority was to break the isolation that many women felt after testing positive. As its chair Rosmarie Rojas pointed out, media descriptions of people with HIV seldom featured women, and so women with HIV could not identify with them. Peer support was a central goal for the Women's Circle, but also to make visible the needs of women living with HIV (Nyquist 1995a). Relevant questions were the effects of medication on women's bodies, and, especially, HIV in relation to menstruation, pregnancy, delivery, and menopause (Segelström and Westerberg 2001).

In 1994, Oasen (The Oasis) was established, first as a network and later as a peer-support group for immigrants from Africa. In 1987, Oasen founder Amadou Jallow, pharmacist at Huddinge Hospital, had joined Nigerian-Swedish activist Ricky Komolafe in working to prevent HIV infection – in cooperation, partly, with the Cultural Association EDO for Africans and African-Americans in Sweden. Other immigrant associations also worked to prevent HIV infection, and some probably organised networks for people with HIV, but it seems that the Oasen was the only peer-support group aimed specifically at African immigrants living with HIV. Jallow and Komolafe noted an increase in Afrophobic attitudes in the early 1990s, as Africans were targeted as scapegoats for the epidemic. They also criticised the practice of routinely offering asylum seekers HIV tests, which they saw as a form of coercive testing of Africans. As they put it: "Wait with the HIV test until the refugee has been granted a residence permit. Train

the interpreters, so that they know how to convey a message about HIV, and, finally, give black people with HIV the same care and treatment as Swedish HIV-positive people” (Hellbom 1992).

Finally, Jallow and Komolafe targeted the Swedish practice of forcibly isolating HIV-positive persons in the “Yellow Villa”, a closed ward in Stockholm’s Danderyd Hospital. Here, people who had violated, or were seen as likely to violate the regulations of Sweden’s Contagious Disease Act, were forcibly detained. Many of its inmates came from African countries. Jallow criticised this and claimed that very few of the detainees had actually spread the virus, but that most were detained because one of the state’s disease control physicians (Smittskyddsläkare) estimated that they had a risk behaviour. Jallow also severely criticised State Disease Control Physician Per Lundberg’s suggestion that refugees with HIV should be refused Swedish residence permits (Hellbom 1993). Oasen engaged in these political protests while focusing on psychosocial support, establishing a meeting point for HIV-positive Africans and their families (Nyquist 1995b; Tottmar 1999; Jallow, interview 2020).

Although the politics of silence had been challenged within the haemophiliacs’ association FBIS already by the end of the 1980s, it was still a highly contentious issue. In 1993, tensions between those who demanded more visibility and those who advocated discretion resulted in a split, as a break-out faction left the group of haemophiliacs that had been meeting at Noaks Ark/Röda Korset. It formed a new group, Haemophiliacs Infected through Medication (Preparat-Smittade Blödarsjuka, PSB) that aimed to organise HIV-positive haemophiliacs and their families. Its co-founder Lennart Lindqvist had also co-founded the FBIS in 1964 and he complained that the Noaks Ark/Röda Korset refused to distinguish between being “guilty or innocent of the infection”. According to Lindqvist, “There’s a hell of a difference if you’re infected by medicine or through hanky-panky (rajtan-tajtan)” (Hafström 1992, 8; cf. Thorsén 2013, 364). The split was formalised in 1992, when Lindqvist declared that the PSB would not join the FBIS in signing a memorandum on

cooperation with Noaks Ark/Röda Korset (Andersson 1992; Janson 1998). From start, the PSB received funding from the Institute for Public Health and described itself as focusing on information, quality of life and peer support. Its motto was to “work without being seen” (PSB vill 1993).

This was also a time when volunteer work became more and more professionalised. With time, the Noaks Ark/Röda korset Foundation had become increasingly structured. Its volunteer activities were somewhat of a hallmark, but as the number of employees increased, the Ark had to differentiate between different types of commitment. It was noted that many volunteered to meet needs of their own, or as a sort of internship, as a stepping-stone to other jobs and careers (Johansson 1997, 69). In 1993, the Noaks Ark/Röda Korset formulated a set of volunteer guidelines which emphasised the need for volunteers to commit to meeting the Foundation’s needs, rather than their own. The Volunteer Coordinator was given detailed instructions: to recruit volunteers, to prepare them for their tasks, and to organise regular supervision for the volunteers. The right person should be assigned to the right job, and – as is implicitly stated – the Coordinator was to convince those unsuited for the job to withdraw after completion of the course (Johansson 1997, appendix 3). The guidelines’ detailed work descriptions were for the benefit of the volunteers, at the same time as it unambiguously declared that the needs of the Foundation and the instructions of the Volunteer Coordinator had priority. In short, it was not always enough just to be a compassionate human being, an insight that led to the formulation of a new motto: “professional voluntarism” (Olsson 1999, 98).

Internationalisation and expansion, 1996–2000

After the introduction of the new retroviral drugs, the number of AIDS-related deaths dropped dramatically. This was paralleled by a drastic change in infection patterns. Of 230 new infections in Sweden in 1998, 52 per cent resulted from heterosexual intercourse, 39 per cent from men who had

had sex with men, 7 per cent from intravenous drug use, 2 per cent from mothers passing on infections to children, and less than one per cent from blood products or transfusions.³⁰

Perhaps surprisingly, the introduction of the new retroviral medicines had little or no effect on the activities and organisation of the various support and self-help groups. According to HIV-Sverige's present-day ombudsman, Simon Blom, there was a ten-year period of mourning before new objectives were defined. Many were still dying, and the survivors faced difficult existential problems (Blom, interview 2022). In 1997, Walter Heidkamp, chair of the Positive Group Stockholm, wrote in an essay entitled "Return of the future":

I have worked my way through the paralysing fear of death that I felt for several years and reached a state of mind where death has become a liberator, a safe harbour in a time of anxiety and fear of death and dying. But now, as people threaten me with an almost eternal life, I have suddenly been deprived of the safety of by and large knowing when I will die (Heidkamp 1997).

Nevertheless, the retroviral medicines that were introduced in 1996 represented a turning point as the number of HIV-infected people who developed AIDS, and who died, decreased rapidly. Noaks Ark/Röda Korset closed its guesthouse after a couple of years, but public support for HIV-related non-profit organisations remained largely untouched well into the new millennium, and HIV-preventive work continued without interruption. Meanwhile, new sets of questions and issues emerged, for those living with HIV – such as discrimination in their working life (En liten bok, 2000).

Towards the end of the 1990s, the FBIS began questioning its past. It now openly gave voice and support to haemophiliacs who lived with HIV, but the old wounds were not easy to heal. A few years into the new millennium, FBIS started work on a white book, *Katastrof på recept – en vitbok om läkemedelsskador* (Prescription for catastrophe – a white book about on medication-induced injuries). Published in 2005, *Katastrof* discussed

the insufficient indemnities given to those who were infected through medication, and how many HIV-positive members had felt betrayed by both FBIS leadership and fellow members.

On an organisational level, however, work continued as usual. The rate of new HIV infections did not diminish and there was still need for medical care, counselling, and support. Self-help groups like PG Stockholm, PG Väst and PG Syd continued their activities, as did the different branches of Noaks Ark. All organisations continued to receive public funding.

One HIV-preventive civil-society organisation did, in fact, change course in the 1990s: the Convictus. This change was not a result of the new retroviral drugs, however. Far fewer intravenous drug users were infected than originally anticipated, but Convictus' members and clients were vulnerable in so many other ways. It had already been restructured into an organisation run by allies of former drug users with HIV in 1993, but five years later, the association broadened its work to include the homeless. For a homeless person, a HIV-positive status might be only one of many problems and it was also especially difficult to administer medication regularly to homeless people with HIV. Convictus argued that its members were most efficient in reaching this group, as the homeless were often suspicious of traditional social services.

In February 1998, Convictus joined with the Johanneshov branch of Stockholm's Links (Länkarna), a Swedish organisation for recovering alcoholics, in opening a day-time homeless shelter.³¹ It was located in Södermalm, Stockholm's inner city south, a traditional working-class neighbourhood undergoing rapid gentrification. The shelter was meant as a contact spot for those furthest removed from regular social services, giving staff a chance to motivate them to seek help for their problems, including testing for HIV.³² Soon, however, neighbours raised protests against the shelter, which sparked a general debate about the role of the voluntary sector in social work. Some of the city's social workers accused both Convictus' and the City Mission's volunteers of lacking professionalism, arguing that giving the homeless food and shelter just made

it easier for them to continue their substance abuse. Instead, the homeless must be forced to seek qualified, professional help, as provided by the municipal social services. The head of Stockholm's Social Agency for the Homeless, Martin Windmar, even termed shelter volunteers "co-dependent". Convictus spokesperson Claes Heijbel retorted that if the homeless were to be helped, it was essential first to establish contact with them. "As a volunteer organisation we have the advantage of not being a public agency. Those who call us co-dependent are not aware of how we work" (Olsson 2000).³³ The debate illustrates one possible point of tension between volunteer-based civil-society organisations and municipal social services: volunteers pointing to their wider social outreach versus municipal services claiming superior professionalism.

With increasing stability and professionalisation, several civil-society groups expanded internationally in the latter half of the 1990s. Many of them successfully applied for grants for HIV- and STD-prevention projects to be carried out in different parts of the world. The RFSU was early out with this, and a growing share of its budget came from Swedish government funding for international development projects. By 1997, the RFSU had initiated STD-prevention projects in Tanzania, Zambia, Russia, Estonia, and Poland. The Association was represented on the executive board of the International Planned Parenthood Federation (IPPF) and it was also active in the United Nations Population Fund (UNFPA).³⁴ Noaks Ark/Röda Korset, meanwhile, had a stated goal of making its "experiences and resources of knowledge available to other countries".³⁵ It coordinated EU-funded and co-funded HIV-prevention projects in Poland, Latvia, Russia, and Mexico, and received commissions from the World Health Organisation.³⁶ During the 1990s, Convictus also expanded abroad. It cooperated with France's treatment collective Le Patriarche, and subsequently received Swedish government funding for projects helping the homeless in the Baltic states (Heijbel, interview 2022). The RFSL followed suit in the early 2000s with LGBTQ-rights projects in other countries (Juvás, interview 2023). Most Swedish support and

self-help groups, moreover, continued their domestic HIV activities; their public funding dwindled only after 2000. By then, however, the non-profit sector had become firmly interwoven in the fabric of Swedish social services.

Conclusions

Overall, the Swedish civil-society response to the AIDS crisis was characterised by conflict, cooperation, and rapid professionalisation. There were disagreements over definitions of safer sex, both within organisations, between organisations, and between organisations and the state. Conflicts arose, for instance, over the RFSL's standpoint that unprotected oral sex was 'safe enough' and between critics and defenders of a 'gay male lifestyle' both within the RFSL, between the RFSL, the RFSU and Noaks Ark, and between the RFSL and the AIDS Delegation. Tensions also arose between FBIS, Convictus, the RFSL and Noaks Ark on the dominance of gay men's perspectives on HIV. The RFSL, on its side, could accuse the RFSU of being an 'organisation for heterosexuals'.

There was also dissension on the question of representation, particularly among peer-support groups such as Convictus and its umbrella organisation RFHP that insisted on the importance of the fight for HIV-positive rights being voiced and led by people who were living with HIV themselves. Here, there were also tensions between those urging people with HIV to openly declare their status, and many members' desire for anonymity. Finally, contention might arise on whether an organisation should focus on peer support or political activism, and concerning the balance between unpaid volunteers and paid staff.

On the grassroots level, cooperation between different organisations' activists was rather smooth. Activists from RFSL joined the RFSU in staffing the Summer Campaigns and the Condom Patrol. Noaks Ark/Röda Korset cooperated with all the other groups, both on a practical level and by generously sharing its resources. Noaks Ark's volunteer courses became important for other associations, particularly Convictus. Finally, the many

contact points between associations organising very different groups of people, including homosexual men and drug users, led to increased mutual understanding and prepared the path towards more inclusive ways of defining solidarity work.

During the 1990s, there was a far-reaching restructuring of welfare services, in what Paul Pierson (1994) has called the “politics of retrenchment”. Demographic changes, economic recession and increased global competition convinced decision-makers that the many hands of the state needed help and that the public sector must be cut back. During this process, voluntary welfare work, once dismissed as degrading charity, was re-evaluated. We argue that the AIDS epidemic hastened this attitudinal change. Sweden, like many other countries with comprehensive, tax-funded health services, came to acknowledge the value of the volunteers’ helping hands. These were not only better at reaching vulnerable and stigmatised populations; they could also, sometimes, work more efficiently than the relatively rigid municipal and governmental bureaucracies. The state was now willing to fund this, and the result was something of a revolution for some of Sweden’s

membership-based organisations. They rapidly increased their outreach and efficiency – at the cost, of course, of dependency on public monies. Individual activists, indeed, often embarked on professional careers, first as employees in non-profit organisations and later in government agencies. In the wake of this came a process of internationalisation, as many voluntary organisations became increasingly involved in international development projects.

In sum, the professionalisation of the voluntary welfare sector would certainly have happened even without AIDS, but the epidemic accelerated the process. When the situation for HIV-positive people as a group changed drastically in 1996, the organisations working with HIV and AIDS prevention were sufficiently institutionalised to continue working as before and widen their scope internationally. Also, their contribution to welfare and popular health were now considered important enough for fund-giving agencies to continue their support. This resulted in the situation we have today, with a largely publicly funded, semi-professional civil society that relies on a combination of paid staff and volunteers.

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Endnotes

- ¹ Lov nr. 224 af 13/04/1988 om ophævelse af lov om bekæmpelse af kønssygdomme. In 1994, however, Denmark re-introduced coercive legislation by adding a paragraph to the Criminal Code which in fact criminalised unprotected sex for people with HIV. Lov nr. 431 af 01/06/1994 om ændring af straffeloven.
- ² Minutes from the Annual Representatives' meeting 7–8 May 1983, 25 §. Kongressprotokoll med bilagor 1983–1984. Serie A1, vol. 8. RFSU Archives. Arbetarrörelsens arkiv och Bibliotek (AAB).
- ³ RFSU Annual Reports 1983–1990. Verksamhets- och revisionsberättelser 1980–2003. Serie B1, vol. 2. RFSU Archives. AAB.
- ⁴ Robert Pettersson married in the summer of 1987 and took his wife's family name, Högström. In September 1989, Tomas Sandberg also married and changed name to that of his wife, Moberg.
- ⁵ Convictus Annual Meeting 21 April 1986. File Medlemsprotokoll Original 86–90. Convictus Archives (CVA).
- ⁶ Convictus Annual Report 1986–1987, 2. Verksamhetsberättelser. CVA.
- ⁷ Ibidem.
- ⁸ RFSL Annual Report 1985. RFSL Archives (RFSLA).
- ⁹ RFSL-rådgivningen Malmö, Information Postcard 1996. Förbundsstyrelseprotokoll med bilagor 1995–1996. Serie A2, vol. 15; Minutes from the RFSU Annual General Meeting 1988, 58 §, p. 48–49. Kongressprotokoll med bilagor 1988. Serie A1, vol. 12. RFSU Archives. AAB.
- ¹⁰ Minutes of the General Annual General Meeting 4–6 November 1988, p. 15. RFHL Archives. RFHLA.
- ¹¹ Statutes of the Foundation Noaks Ark/Röda Korset 1987. Bernhard Grewin's Private Archive (BGA).
- ¹² Noaks Ark/Röda Korset Annual Report 1988, Svensk insamlingskontroll's Archives (SIA).
- ¹³ Noaks Ark/Röda Korset Annual report 1 October 1987– 31 December 1988; Noaks Ark/Röda Korset Annual report 1989. Kungliga Biblioteket (KB).

- ¹⁴ Call for a Meeting with Noaks Ark Malmöhus 16 December 1987; Minutes of the Board of Noaks Ark Malmöhus 9 January 1988, § 2, Bil. 1 Normalstadga för Noaks Ark-förening; Minutes of the Board of Noaks Ark, Sweden, Stockholm 24 January 1988, § 3. Positiva Gruppen Syd Archives (PGSA).
- ¹⁵ "Noaks Ark får massiv kritik", *Göteborgsposten*, 15 August 1990; Minutes of the Board of Noaks Ark Göteborg 16 August, 19 September, 14 November 1990. BGA.
- ¹⁶ The branches were Stockholm, Malmöhus, Northwestern Skåne (Helsingborg), Gotland, Östergötland, Värmland, Gävleborg, and Kronoberg (Växjö). Noaks Ark Malmöhus Annual Report 1993, p. 2. Lena Söderquist's Private Archive, Malmö (LSA)
- ¹⁷ Convictus Annual Report 1991/92, 2. Verksamhetsberättelser. CVA.
- ¹⁸ Minutes of the Convictus Board 5 May 1992, § 75. Styrelsemötesprotokoll original, 90, 91, 92. CVA.
- ¹⁹ Positiva Gruppen Annual Report 1989. Archives of Positiva Gruppen (PGA).
- ²⁰ Positiva Gruppen Annual Report 1989. PGA.
- ²¹ Minutes of the PG Board 7 May 1990. PGA.
- ²² Minutes of the PG Board 7 May 1990; Minutes from a Discussion in Positiva Gruppen's Ideological Working Group (Idépolitiska gruppen) 25 March 1990. PGA.
- ²³ Ibidem.
- ²⁴ Positiva Gruppen Annual Report 1989. PGA.
- ²⁵ Meeting with Representatives for HIV Positive Groups in Sweden, 18 January 1990. Convictus Protokoll m.m. 1986–1990. CVA; quote from RFHP Annual Report 1991. Verksamhetsberättelser. Hiv-Sverige Archives (HSA).
- ²⁶ Members from start were Positiva Gruppen Stockholm, Föreningen NU (The Association NOW, for people infected via a blood transfusion), Hivpositiva Blödarsjuka Unga (Young Haemophiliacs with HIV – in practice only one person without any support from FBIS), Föreningen PLUSS (The Association PLUSS, an association for straight men and women with HIV), and Malmö-based Positiva Gruppen Syd (Positive Group South). RFHP Annual Report 1999. Verksamhetsberättelser. HSA.
- ²⁷ Convictus Annual Report 1992/93. Verksamhetsberättelser. CVA.
- ²⁸ Minutes of the Convictus Board 3 June 1996, § 8; Minutes of the Board 4 December 1997. Protokoll 1993–1998. CVA.
- ²⁹ Convictus and Kaliber (a short-lived local peer support group for drug users with HIV in Malmö) joined in 1991, followed by PLUS Göteborg (Göteborg City Mission's support group for people with HIV), Positiva Gruppen Väst (Positive Group West), Positiva Gruppen Örebro, NIWAG+/S (Nordic Immigrant Working and Action Group for People living with HIV/AIDS in Sweden). Föreningen NU, Kaliber, Föreningen PLUSS, NIWAG+/S and PLUS Göteborg discontinued their activities after only a few years, but in the 1990s, two more long-lived member organisations joined, Kvinnocirkeln (Women's Circle) and Oasen (Oasis – for African immigrants). RFHP Annual Reports. Verksamhetsberättelser. HSA.
- ³⁰ *Smittskydd* 4, nos. 4, 7–8, 10 (1998); *Smittskydd* 5, no. 1 (1999). In addition to this, there were 20 new cases where the cause of infection was unknown.
- ³¹ Länkarna is a Swedish seven-step programme, inspired by the American AA-movement, for people with different types of chemical dependency. <http://www.rikslankarna.se/>
- ³² Minutes of the Convictus Board 20 October 1998, § 4. File Protokoll 1993–1998. CVA.
- ³³ Minutes of the Convictus Board 20 October 1998, § 4. File Protokoll 1993–1998; Quotes from Convictus Annual Report 1999. Verksamhetsberättelser. CVA.
- ³⁴ RFSU Annual Report 1997, p. 23. Verksamhets- och revisionsberättelser 1980–2003. Serie B1, vol. 2. RFSU Archives. AAB.
- ³⁵ Noaks Ark/ Röda Korset Annual Report 1999, p. 13. SIA.
- ³⁶ Ibidem.