

“AIDES is an organization of seroconcerned people”: An Interview with Dr Bruno Spire¹

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Rafał Majka: AIDES was founded several decades ago, in 1984. Throughout the years, it has gained a lot of experience and knowledge and has always been eager to share. The founder of AIDES, Daniel Defert, sought to create “a place of reflection, solidarity and transformation.” How have the ideas been practiced by AIDES?

Bruno Spire: Solidarity came first. The first actions were performed under the umbrella of solidarity. People were very shocked by the new epidemic in the 1980s and everybody in AIDES knew someone who got infected or was personally confronted with HIV. A lot of people were diagnosed with HIV, and nobody knew what to do, so there was a need of support in a time when families were excluding people with HIV. Some people had to conceal they were gay, as homosexuality was stigmatized in many communities. People were alone and solidarity was what was needed. It was practiced as self-support groups, people informing each other about the disease and sharing ideas on how to resist in the absence of any treatment. Then a couple of years later, at the turn of the 1980s and 1990s, there was a big schism in AIDES. Some members of AIDES who were professionals thought that the response to the HIV/AIDS crisis needs to be professionalized so that AIDES should become a space for doctors and social assistants, but it was against the idea of Daniel Defert who was defending the model of community-based activities. It was not that all members had to be volunteers; volunteering was not enough. AIDES had to be able to have staff, but the staff should be anchored in the community. We didn't want to be like a private organization hiring doctors and nurses. We wanted to be a community-based organization where people using their life experience were able to be involved in the response. And so there was a split. Those who wanted to have a type of service organization, and who are now in a group called Group SOS, formed of ARCAT-SIDA and it grew to include other services organization, but politically they didn't wield any power. They were just interested in providing services, and they are doing a really good job, but it's not the project of Daniel Defert. And then the social transformation... The first social transformation was that the rights of patients were recognized, the rights of all patients, no matter their serostatus. Now when people go to hospital, they must be fully informed by doctors. This is a big change compared to the past, thanks to the HIV crisis and its related activism.

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Another change was the participation of patients' representatives in all the hospital boards where decisions are taken. It's called "health democracy" and that's also a transformation that came from the HIV fight. AIDES was instrumental here. Patients' organizations act like trade unions. We think that we are the trade unions of patients. That's the role of associations – to defend the rights of patients in the health system. We are now able to sit at the table and it's not possible to make big decisions without any patients' representatives. That's in the law and it was voted in 2002 on the rights of patients. It's not only for HIV, but it was HIV patients who conducted this fight. And in more recent times there was also a big transformation in prevention which made it possible to do lay testing by people who are not doctors or nurses. It happened during my presidency [2007-2015]. AIDES was not expected to do any HIV testing. It had to be done in healthcare institutions with doctors, but we were able to demonstrate through research that this procedure of testing, when it's done by lay people, is efficient, even more efficient because it attracts people who don't want to go to conventional testing centres. We don't steal the patients of regular doctors. We attract other people that would not go anywhere if there weren't any community centres. They come to us because they feel more confident around people from their communities, especially gays who are not very educated and take a lot of risk. They prefer to be tested at a community organization where there's no moralizing like "oh, it's bad that you're not using condom." And we managed to get the right to do the testing.

Another example of a social transformation was the right of drug users to have a substitution therapy and needle and syringe programs. Thanks to the AIDES fight, drug users were recognized by the society as people who need care and not only prison. This fight is not over yet because people who use drugs are still negatively viewed. There is still a lot of stigma against drug use, but at least people now think that those who use drugs need care. Harm reduction did not exist at the beginning when Daniel Defert created AIDES, and AIDES started the concept of harm reduction with progressive doctors and addiction specialists. We made an alliance with the doctors to push the recognition of harm reduction as the national policy for drug users and now it's in the law. Harm reduction was recognized in the public health law in 2004, but there were some reservations. For example, we had to convince the authorities that safe injection facilities and drug education, which we have been doing in AIDES programs, are good regulations. We had to do an experiment to show that when you help drug users to inject safely, it has a positive impact on their health. We then set up a research program showing the positive outcomes of drug education by peers. Drug users would inject substances in the AIDES facilities, of course they had to bring their own drugs (we don't provide), and when they were making a mistake, they were stopped and educated how to inject properly and safely. There are several courses like this and we did interview the participants 6 months and 12 months after the course, and we could show that they were much more empowered not to make any mistakes. Also, we were able to show that people who inject drugs in harm reduction facilities are at a much smaller risk of developing infections around the places on their bodies where they inject. And the law changed and now it's possible to do these education programs.

The other social transformation was of course PrEP and sexual risk reduction. It was a big fight and took a lot of years. Other community organizations and a number of doctors were against AIDES in this area and in the beginning we were alone to say U=U [Undetectable=Untransmittable]. We didn't say U=U because it wasn't this slogan at the time. We used "treatment as prevention" (TasP), but for a lot of people it was very controversial – for medical doctors and also for ACT UP Paris, which is an activist organization that has been fighting a lot for the rights to access to the treatment, but in prevention they were like condom Taliban with a mindset like "if you don't use a condom, you're a criminal, you should be excluded from the gay sauna, from the gay darkroom." My sense is that it was a strategic mistake for them, because, just like us, they are trade unions of people, they should represent people who have problems with condoms and not fight them. It's like a workers' trade union would say to the members: you are so lazy, you should work 7 days on 7 and give up your holidays to save the company. But we were able to push the researchers to do PrEP experiments, and we helped them to do the research. AIDES was involved in the IperGay study which proved the positive effect of intermittent PrEP and the government was finally convinced that PrEP should be authorized and fully reimbursed. France was the first country in Europe to reimburse PrEP.

R: It's a very big success for a social movement...

B: Yes, a big success. It also opened the way to a model of the sexual health centre. Before the implementation of PrEP there was almost no sexual health-oriented place except one in Paris called 190, which was a small centre, and there were no guidelines for sexual health at the national level. Now you have all the doctors claiming that they want to develop sexual health clinics in which gay people or sex workers can do tests for STIs. Doctors want to do PrEP and counselling programs, but back in time they were going on with the condom mantra. Thanks to the IperGay study, it became possible to establish the sexual health centre model and to attract numbers of people to such places where they are offered STI check-ups, counselling and proctology, all in one place. In the PrEP study, half of the participants got PrEP, the other got the placebo. Yet, when people got involved in the trial, they didn't want to give up because they were happy to visit these facilities, they needed them. When you do use condoms, nobody checks your STIs, and you can get STIs even when you are wearing a condom, because a condom is usually for anal or vaginal sex, but not for all sex. In the studies it is estimated that less than 5% of people use condoms for oral sex, and it's this way you get most of STIs. Now AIDES contributes to the new strategy of sexual health which is run by the government. However, everybody tends to forget what they were saying before in the matter...

R: The name of the organization takes a plural form. Again, it was the idea of Daniel Defert to put the name in the plural so that different kinds of help AIDES seeks to provide are emphasized. What kinds of help do you provide?

B: As a social movement, the pillar of our help is collective empowerment, I would say. It's the possibility to put people together, use their personal experience and make it a collective experience. When

they are brought together, people realize that everyone has a different experience. There was a situation that will stay with me forever. I was animating one of the first, we call it, therapeutic groups. It was at the beginning of the antiretroviral therapy era and there were still people with HIV that didn't want to go to treatments because they feared side effects, a bit like people that don't want to be vaccinated today. And so, we were putting up groups for weekends, two days, where people were individually speaking about how they deal with treatment. They spoke about the fear of treatment, they exchanged information, they shared tips how to be adherent. In those days treatments were very complex. You had to take some pills with food, other pills without food, it was quite complicated. And there was this one guy in this group, weighing maybe 40 kilos, completely skinny with almost no more CD4s [lymphocytes that help to fight infection] and he was saying: *I'm of German origin, I don't need any treatment, I don't want to take pills, treatments will kill me, it's horrible, I don't want them, my doctor tries to convince me and I will never accept these treatments coming from a pharmaceutical company that just wants to make profits.* He stays two days with us listening to the experiences of other participants, and at the end of the weekend he says: *OK, I'm going to see my doctor tomorrow and tell him that it's OK for me to start the treatment but only with Efavirenz,* and the next day he went to his doctor and said he wanted this particular drug. The doctor was so happy that he even didn't bargain to find another drug. I met this guy one year later, and he recovered completely from most of his problems, and he was very happy with this treatment. And the doctor was also very happy because it was this collective help that was able to convince the patient. The collective experience and the validation of knowledge through peers. And I think that the basic thing in AIDES is the collective ways of helping.

In the past we experimented with some services like hiring social workers, renting apartments for the social workers to work, but it didn't turn out right. It's important but it's not the rule of AIDES to do this. There are several other institutions which can do that. We hired social workers and we had numbers of people coming not interested in any social transformation, seeking help only for themselves, queuing in lines to see the social workers of AIDES just because their social workers didn't do their work properly. We decided to stop this kind of help. Now there are many things that we are considering to do in the future that might need that infrastructure. For instance, for illegal migrants who come to France and don't have any place to go, who live with HIV. We could imagine such social services, but they would have to be performed by non-social workers who have this experience of arriving in France with a very precarious status. They could help the new ones who arrive to find a job, to organize documents to get a legal stay in France and to welcome them in apartments that could be rented by AIDES. That could be a possibility. That could be done in the future. It's not in the agenda yet, but it's there in the thinking. It's more the colour of AIDES to do activities with people who have knowledge of life than with people who have just university knowledge or a diploma.

R: With peers from inside the community rather than people from outside the community.

B: When you were visiting our Spot Marshall in Nice or Spot Longchamps in Marseille, you saw that we also have doctors, but the important thing is that doctors do not have the power, the power is the lay people. The board of AIDES is elected by the volunteers, not by the employees of AIDES. The doctors are employees and they, of course, have to share the values of AIDES – we don't want any racist or homophobic doctors, but we want the doctors to stay "technical" like the AIDES accountants who do all the bureaucracy. We cannot do our 45 million Euro yearly budget with lay people, it's too technical. It's the same with medicine. We are not against "technical" people, but we think the power has to come from lay people, the inspiration has to come from lay people.

R: You have also organized the space in your spots in a way that makes the patient feel close to the sexual health advisor – the doctor sits not behind the desk but next to the patient, so it's not like a formal meeting with an authority figure but rather a chat with a peer.

B: All the things that make up the relationship between the provider and the patient are changed when you compare it with the conventional hospital setting. The principle in AIDES is that if you are helped, you should consider becoming a member of AIDES, getting involved in the activities for the community. The first people who were tested through lay testing would say that it was fantastic what we were doing, and we would say to them: *yes, it's fantastic, please, join the staff and do it also for the community*, and some did join and are doing community work. We have to mobilize people so that there is not this divide between users and those who have the knowledge, even the lay knowledge. Now and then there are some tensions in AIDES because sometimes lay people who do lay testing behave a bit like doctors, conventional doctors, and I think it's a danger. You can't think that you know things and the other person doesn't know anything. You have to be on the same level, equality attitude. It's part of our job in AIDES to attract the public we target so that they could become members as well.

R: You can also learn a lot from the people coming to your spots because they share their own intimate socio-cultural experiences.

B: Yes, but not only learn. The learning part is also there because people usually arrive with what they have heard and share. However, it is important to give them the idea that they could also volunteer in AIDES. To be a volunteer means that you have been affected by HIV, whatever that may be – your friend has got infected or you need to get tested, or you need to take PrEP, so you are legitimate to be a member. It's important to show that AIDES is open, that we need more people.

R: Why is it important for social organizations to adopt the community-based focus?

B: The founder of AIDES, Daniel Defert, from the beginning wanted AIDES to be a community-based organization, which works with, and not a service organization, which works for. Working with means that you need to recognize the knowledge acquired by experience and not be fully led by the knowledge acquired by training. There are four pillars of community-based organization. First, you have to

imagine the activities from bottom to top and not the other way around, so it's not the president of AIDES who decides that, for example, tomorrow everybody will be providing testing services. Actually, it's the people on the ground who come and say that people in the community ask to be tested and they need non-judgmental peer-based testing, so that's how testing comes up as important. The second one is recognition of lay expertise. The third is social transformation and the fourth is collective process, the magic of the group, collective intelligence. Sometimes you put up a group in AIDES and they provide answers to a question which can be difficult to work out on one's own. You bring ten people together and after one hour they arrive with a number of ideas and a ready plan of action for the next year. That's the magic of AIDES, really, to decide collectively.

R: What do the communities you work with think of your approach?

B: Well, there are people who understand what we have been doing and they like this approach. Yet, there are many who actually do not really understand what we are doing. Some of them think that we are just an activist association claiming rights and claiming things. Others think that we are just a service organization and we don't transform anything. We are in kind of a centre position between those who are purely activist organizations fighting the government on laws and others who are completely service organizations. Our in-between status is a bit complicated for a lot of people to get. For us, the advocacy part has to be based on what we observe in the field. That's why we need to be inspired by what the militants find in their daily activities. The thing I hate is the activists at conferences who represent only themselves... They are super activists, you see them at all conferences, invited to talk in the name of patients, but most of the time they are not linked to any organizations, they don't see any other patients than themselves... OK, they are HIV positive, but you cannot pretend you represent a group of people only because you are HIV positive yourself, so it's a kind of tokenism which is used especially in all these international organizations, and this is a very Anglo-Saxon thing. They are free electrons, not connected with any collective group, and when you are discussing things related to patients, it is important to be involved with a group. People think about things said by those whom they see at conferences and what I'd say is that our position between service organisations on the one side and activist organizations on the other side, the fact that we are in the middle, when we say something, what we ask, what we demand, it's based on what we have observed in the field and not only on what we think... It has to be corroborated by facts. For example, at this moment there are a lot of discussions about so-called injectable therapy, that is, instead of pills, you take an injection every two months. The producer of the therapy has not demonstrated that the injectable therapy works better. Recently, doctors have started to voice a need for this drug and the producer is asking us what we, in AIDES, think about it. So what we are doing now – and this is the answer that I'm giving to all who want to know our position on it – is a survey among the people who are connected with AIDES to get to know what they think and only then, after the survey has been done, we can arrive at some advice. People approach me because they know I'm in AIDES, but my personal opinion is not something that can be given as advice. In such situations a study has to be done so that the community gets represented. Representing the community means that you have to be connected with the community and not only decide for them.

R: The AIDES motto is “Le seul moyen d’arrêter le sida c’est vous” [The only way to stop AIDS is you]. Why is an individual, the “you,” so important in the fight against the HIV/AIDS crisis?

B: It is you because you can join us, the movement. You can do it. You can become a volunteer, a part of the movement. It’s not a moralistic way to say: oh, if you behave well, you can stop AIDS. It means: come with us. It’s the community-work context. Come with us, you can be a donator, an actor, a volunteer, there are different ways of being with us. You can be what we call an actor: you can’t vote if you’re an actor, you have fewer rights in AIDES, but you have to attend the meetings where you discuss the values of AIDES and after that, if you agree with what you’ve heard, you share the values, that is no homophobia, no stigma, you sign an agreement and you can be part of the activities, working either with our volunteers or our staff. If you want to go further, be an elector, be part of the decision process, you need to be a volunteer. To be a volunteer you need to do a three-weekend training in Paris. After you officially become a volunteer, you gain the right to vote and to be elected. There are also some other possibilities – you can work in AIDES and have a salary, but if you are an employee of AIDES, you cannot vote. The political decision and the power in AIDES belong only to volunteers. The staff cannot vote and it’s a very important regulation. When I was the President of AIDES, we decided to stop the specific help for patients at home. The context is that in the 1990s there were many people with AIDS who were too sick to do the cleaning, shopping or food preparation activities on their own, so we provided help. After many years of ART [antiretroviral therapy] this kind of help didn’t need to be provided. However, the people who had been delivering this kind of help were trying to reinvent themselves as help providers in the context of other diseases and other things. We then decided that it’s not our role, so we closed down those services and with the money we saved, we were able to do more therapeutic education or other prevention activities that are more useful than those that were relevant in the 1990s but are not relevant any more in the era of effective antiretroviral treatment. If the staff was on the board, it would have been impossible to close those services, that is why the board of AIDES needs to be excluded from the voting process.

R: Through all these decades, AIDES has worked with different communities. What inspiring practices of self-organizing, mutual care and social solidarity have you seen and/or helped to develop?

B: We have approached and worked with several communities in the history of AIDES. First, it was the gay people in the 1980s. In the 1990s came the drug users. Then the migrants and more recently also transgender people. What is most fascinating in this is the solidarity between these groups. It’s not an apartheid of groups and people are learning from each other. With chemsex on the rise, gay communities need a lot from drug users in terms of harm reduction. The borders between the groups are collapsing because even if there are some specificities, there are a lot of common things between gay chemsex and drug use in terms of legal barriers. Through this solidarity we were able to create the identity of seroconcerned people. Another barrier which has started to collapse recently is that between HIV-positive and HIV-negative people. Before PrEP only HIV-positive people had to take pills and now when PrEP has been introduced, if you see someone taking a pill, you don’t know if it’s

PrEP or ART. Now people understand each other because, with HIV-negative guys who take PrEP, it is like you must not forget to take your pills whatever your status. It's this kind of solidarity in terms of your relationship with your treatment, your doctor, the health system. AIDES has created this. It's also very positive to meet, for example, transgender people, when you didn't have any idea how they were living. Now I'm doing work on transgender people living with HIV and it's a study that my research team [part of the French National Institute for Medical Research (INSERM)] does with AIDES and another association (Acceptess-T), a sex worker and transgender organization based in Paris. It's a national survey, quantitative research. We are trying to interview all the transgenders living with HIV in France.

R: You mentioned the seroconcerned identity. Could you elaborate on what it means to you and to AIDES?

B: The seroconcerned identity is a concept I developed when I was the President. AIDES is an organization of seroconcerned people, which means that you are concerned – either you are HIV-positive, or exposed to HIV, or have people around that are HIV-positive and you are affected because you care about them, or you can be just angry about discrimination and be concerned because you want to change the society. We are then all seroconcerned and not the positive on one side and the negative on the other side.

R: What do you see as the role of the state (city authorities, government officials) in the fight against HIV/AIDS epidemic?

B: The role of the state should be first to have a political vision concerning the HIV fight, and increasingly HIV is not on the top of the government agenda. They know it's important, but my fear is that, especially with the Covid-19 pandemic, HIV means too small a number of people to be equally important. My first expectation from the government is to recognize that HIV is still a problem. We are almost 38 million people living with HIV in the world. There's no cure and no vaccine, so the authorities have to be aware of this. The second expectation is the financial support given to organizations that do public help activities. We should have money. We need to be sure that the funding is continued. We also expect that the decisions have to be taken with us – the government needs to apply the principle of health democracy and not make any HIV-related decisions without the people concerned. We should also, I would add, take the lesson from the HIV field to other pandemics, which hasn't been done especially in the context of the coronavirus crisis. It's a bit the opposite to the HIV crisis. For the HIV crisis the French government did not take any decisions for years. The crisis arrived in 1983 and the first decision was taken in 1986. It was a specific decision, giving the possibility to buy needles in a pharmacy without a prescription. But the government of Mitterrand didn't pronounce the words HIV or AIDS ever; it was too politically risky for them, they were not interested... However, in 1988 the government had to take a certain number of decisions, but we had to push them to take those decisions. With the coronavirus it is the opposite, everything is decided by the

President who doesn't want the advice of the French civil society. He knows better than anyone else, and all is top to bottom. And now they are a bit angry because there are some people who don't want to be vaccinated... Everything was imposed from top to bottom, and there are no group decisions to convince those who are not willing to take the vaccine. The civil society is not involved, the trade unions are not involved... And there are a lot of associations, not only health associations but also sport associations, and associations in the countryside or in cities, where people could have been consulted, where group discussion could have happened... The French authorities don't take the experience of HIV when making decisions. It's like it has never existed. They don't learn the lessons.

R: What challenges do you see as emerging in the fight against HIV/AIDS in the near future?

B: The international aspect. Today we cannot do activities only with the domestic view. HIV is mostly present in Africa, also in Asia, and it's also a pandemic, so the model of AIDES and the community vision we have could be ushered with other organizations in the world. We have been doing that since the very beginning, but now it has to be even more developed. It started long before me, with bilateral collaborations between AIDES and associations in Mali or Morocco. We also had a bilateral collaboration with a Polish organization in the 1990s on the harm reduction experience and it was very close to the ideas of Daniel Defert. So, we had bilateral collaborations in Eastern Europe, in Romania and Poland, and in Africa, and after a while the French government tried to push us to develop the collaborative project even further, but we were a bit hesitant about this because we had the impression that we as a country in Europe still have this kind of colonial way of doing things. We then decided to create Coalition Plus in 2008, together with three other associations, Moroccan, Canadian and Malian ones. This organization now has 14 members and all the members are on the board and everything is shared globally. The governance is not in AIDES. We give money to Coalition Plus. At the beginning it was 100% and now it is maybe a third of its budget because they were able to develop and find other sponsors. Coalition Plus then carries out many activities. Each member receives 1000 Euros, and they can do what they want with the money. It is different with formal, institutional grants where you need to do exactly what the grant states. For example, you want to organize a congress with organizational members in your country, make a democracy in your organization – with formal grants you don't have the possibility to do it, you don't have the money to do it. A free grant allows the members to do what cannot be obtained with a formal grant. However, to be a member of Coalition Plus, you need to meet very specific criteria, including a community-based focus. People living with HIV have to sit on the boards. We don't fund boards which are composed only of people from institutions. It has to be controlled in terms of governance by the very people the focus of the organization is related to. When an organization applies, we conduct meetings and check whether they meet a number of criteria, before we decide whether to accept them or not. If we decline, then it's always possible for the organization to implement some changes and reapply. Today in Coalition Plus there are 14 official members and 100 partners in 52 countries.