

CIANE - Collectif interassociatif autour de la naissance

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QueFaitLeCIANE

CIANE → Interventions

Contribution to the roundtable on the topic *Patient Organizations Alliances : is Activism Sustainable into Large Coalitions ?* (Bernard Bel). MEDUSE international conference on Governance, health, and medicine. Paris, 10–11 July 2007.

The CIANE (Collectif Interassociatif Autour de la Naissance) is a French coalition of non-profit consumers of maternity care associations. It originated from the CISS (French interassociative health collective) which was founded as an informal coalition in 1996 before getting officially registered as a non-profit association in 2004. The CIANE has followed the same path: it was founded in 2003 and registered in 2007. The major incentive for these collectives to officially register as non-profit organizations is that this procedure constitutes the first step in the process of obtaining an agreement from the Ministry of Health as a patient organization or health service user organization. These organizations have to get this agreement to take part on behalf of the patients, users or consumers they represent- in the committees and in the study groups under the administration of the Ministry of Health.

The CISS currently gathers 25 member organizations and the CIANE 140. These figures are not significant inasmuch as some member organizations, such as *La Leche League* or *Familles de France*, are large federations whereas many other member organizations are small birth-activist groups with five to ten members working on a local scale. As the CISS and the CIANE are interassociative collectives it is difficult to estimate how many individual members both coalitions gather. Our estimate is that the CIANE represents 150,000 with perinatalty directly concerned citizens (knowing that there are 850,000 births per year in France).

The institutionalisation of the collective has been an issue of a long-lasting debate within the CISS. It is one of the main concerns of the CIANE, which is at present in a transition period.

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Problems

1. To negotiate policies or to communicate with the public, bureaucrats have a tendency to prefer interacting with a limited

number of persons or groups. The first person or the first group acquiring a reputation of cooperative opinion leaders are likely to remain in the same privileged status unless challenged by competing activists. This happens quite frequently to the CISS and they keep reminding officials that their coalition does not represent “all patients, which means that negotiations should be extended to a larger number of societies.

In the CIANE we might indeed face the same problem in the long run. Even now, a very small number of representatives are interacting with officials under the banner of the CIANE. To a great extent, this is due to the experience and expertise they have acquired in their professional environment and/or in voluntary work for the CIANE or its affiliates. To a lesser extent, this is due to the fact that they live in Paris!

2. When leaders come to the fore, ordinary members tend to delegate all powers to them, including that of taking care of daily business in the society.
3. This problem is more acute in the CIANE than in the CISS because of the age group and social status of many birth activists. Sometimes it is hard to convince a young mother that she is capable of doing efficient work for the society, even though she may already have a professional experience and/or a high standard of formal education.

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Solutions

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1) Focusing on the empowerment of activists

This is indeed the response to problem (3) exposed in the preceding section. Though there is no French equivalent for ‘empowerment’, I often quote a famous definition (and great insight) by Félix Guattari. In his view, empowerment means *a collective construction of subjectivities*. This is not an oxymoron. It means that you do not get power as an individual, but from the sense of belonging to a **group**, although this power will remain your own regardless of the strength of the group. Empowered parents are not only the focus, the beneficiaries of perinatal care, they should also take initiatives and become actors of social change. Involving fathers and siblings in this process plays a significant role in social mobilisation. See my paper [liste-naissance@yahoogroupes.fr - the birth of a virtual community \(2002\)](mailto:liste-naissance@yahoogroupes.fr)[?].

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2) Using modern communication tools

To maintain a close contact between leaders and grassroots activists, we need to facilitate a democratic sharing of information. For this, we use Internet tools (discussion lists, blogs and websites). For instance, the CIANE is registered as a standard non-profit society with a standard governing body: president, secretary etc. (In order to avoid confusion, we

discarded the option of a collegial body - of a 'Mexican army' of co-presidents.) However, we expect the governing body to enact decisions worked out collectively by a 'technical committee' which is nothing but a discussion list.

A drawback of this democratic decision-making process is that all the information transits on the CIANE discussion list, making it difficult for members to stay stick to the current topics. To compensate this, we create work groups for various topics, and each work group may create its own discussion list(s) for the time the group remains active. (Creating a discussion list is a very simple task.)

Using a blog for the CIANE website makes it possible to publish motions based on consensus. How is this achieved? First we write a tentative statement and discuss it on the CIANE list. Then we publish it on the website, send out announcements and wait for comments on the website. After a few months, if the revised version remains stable and uncommented, we consider that it has been adopted. This type of consensus is indeed subject to revision if challenged later, when conditions have changed or new people have joined the CIANE. From this viewpoint it works similarly to (and has the same legitimacy as) consensus in medical practice.

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3) Training

After its registration, the CISS was granted substantial funding from the State, which contributed to its development over the whole territory and to a professionalization of its activities. Funding also made it possible to set up training programmes for citizens eager to join the governing bodies in hospitals or to sit in national/regional health committees. This training has been strongly encouraged by Health authorities in France.

For responsible citizens, training should cover basic medical knowledge on recurrent topics, a fair knowledge of legal issues, and a 'bag of tricks' to interact on an equal stand with health professionals and bureaucrats sitting in committees.

The CIANE will implement its own training programmes once it has sufficient funds and people to start in this direction. However these programmes should focus on medical and legal knowledge specific to the domain of perinatality, as it will be more efficient to send trainees to other institutions such as the CISS and the INSERM.

The CIANE's specific programs will rely on material currently being gathered on the CianeWiki website.

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4) Encouraging *roles*

At least two types of roles can be found in action group leadership:

- Implicit roles are the ones that persons may spontaneously pick up according to their psychological and professional profiles. Thus, a

lawyer will 'naturally' become a legal adviser for the society, whereas a computer engineer will take in charge Internet communication tools.

- Formal roles are attributed by the group: secretary, spokesperson, etc.

It is important to pay attention of the complementarity of these roles in the group and to avoid clashes between different visions instilled by actors belonging to different 'spheres'. In the [CIANE](#), for instance, we need to adjust and to use the full potential of several 'cultures', such as corporate and scientific/educational cultures, that are often opposed in society at large. In general, working in a cooperative turn of mind requires taking sufficient distance with one's own experience of leadership in a competitive society.

A swapping of roles may also prove successful on the long term. For instance, there is an evident risk in relying on a single person for the management of Internet tools. When starting the CianeWiki website I delegated the installation and setup to another engineer and we used popular software that many technicians will be able to maintain. Another type of delegation occurred when the [CIANE](#) was first registered: we insisted on having 'younger' people on the governing body, thereby excluding pioneers - except for the president. In this way we promoted a new dynamics in the coalition.

' ' Regarding roles in collectives, see D. Vercauteren, T. Müller & O. Crabbé, *Micropolitiques des groupes pour une écologie des pratiques collectives*. Forcalquier: HB Éditions, 2007, p. 167–178.'

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5) Developing authoritative sources of information

The AFAR, a member organization of the [CIANE](#), created a shared database ([RechercheBibliographique](#)) of scientific publications on perinatality. This database is operated in a cooperative manner and it is publicly accessible. It is currently used by parents, journalists, student midwives, etc., and the expert members of study groups. Recently a study group of the [HAS](#) requested us to extract an index of EBM literature relating to 'physiological birth'.

This first 'activist' use of our database occurred in 2004 after AFAR's campaign on episiotomy. The [CIANE](#) filed a request for a study group along with the National health insurance ([CNAM](#)) and the National College of Gynaecologists-Obstetricians ([CNGOF](#)), and it provided more than 100 scientific articles in support to the suppression of 'preventive' episiotomy. At the end of 2005, recommendations for fair practice were published though in the meantime this project had been 'hijacked' by [CNGOF](#) for bureaucratic reasons.

More recently, the [CIANE](#) has been involved in four study groups of the [HAS](#):

- Antenatal screening for Down's syndrome (over);

- Fundal pressure (over);
- Induction of labour (pending);
- The follow-up of normal pregnancy (pending).

We consider that the first three ones are full success stories. The new recommendations on antenatal screening and fundal pressure are exemplary, and the ones that the induction group are currently writing down are of great quality. The last group is a total failure, because of a poor management and the unwillingness of many participants to revise the fundamental beliefs on which French obstetrical practice has been stuck for decades. The [CIANE](#) decided to suspend its participation in the study group.

- > Regarding [HAS](#) and patient organisations, read Etienne Caniard's contribution to this conference, in [French](#) or in [English](#).

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6) Offering cooperative tools for the coordination of groups

CianeWiki is a new undertaking of the [CIANE](#). It aims at developing a common Internet space for all its affiliates, taking advantage of Wiki technology. The approach is similar to those of [Wikipédia](#) and [Ekopedia](#) with the notable difference that most pages are not created by anonymous people, but by identified groups belonging to the [CIANE](#) or agreeing with its goals and the site's guidelines.

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The example of EGN 2006 (EGN2006) CIANE's political agenda

- During their closing session of [EGN 2003](#), its organisers suggested that the next *États généraux* be managed by consumers.
- [EGN 2006 \(EGN2006\)](#) have been constructed on a cooperative approach: call for proposals of thematic workshops in which medical specialists and customers would contribute on an equal stand.
- Each workshop was documented months in advance and it had its own forum on the website.
- Workshops have been recorded and their full transcriptions are available on the website ([EGN2006](#)).
- Once the event was over we opened a [public-archive discussion list](#) in which participants and supporters could extend discussions and evaluate the workshops.
- From October to December 2006 the [EGN list](#) worked in collaboration with the [CIANE](#) discussion list to elaborate a [political agenda](#).
- The [political agenda](#) received official support from several professional groups.
- This year, the political agenda has been submitted to politicians

contesting elections.



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