Analysing patient civil society using the CIVICUS Civil Society Index

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Background

Patient groups have become important actors in health care and much is talked about them - but little is known about patient organisations, self-help organisations, disabled groups, consumers organisations - in society as well as within the arena of patient organisations

- Duplication of efforts
- Impression of intransparency
- dialogue and cooperation in patient CSI limited
- Little dialogue with broader civil society
Civil society is “the arena between
- family,
- government,
- and market,
where people voluntarily associate to advance common interests.”

Synonyms:
non-governmental sector, third sector
Definitions II

Heterogeneity of (patient) civil society

Public interest NGOs (PINGOs)
Quasi public NGOs (QUANGOs)
Business initiated NGOs (BINGOs),
My own NGOs (MONGOs)

► Scope of this study limited to:
- self-help organisations, disabled groups, consumers’ organisations
- as health care users or for health care users
► Patient interest NGOs (PATINGOs)
Targets

...To generate knowledge and write an outline report about the German patient civil society as a basis for further dialogue at national and international level.

... To apply and test the usefulness of analytical tools for civil society in studying the subsector of patient civil society.

Methods and materials:
Secondary analysis
- of scientific literature, legal documents,
- websites and other information of PATINGOS
- data and information from public bodies
Analytical framework: CIVICUS Civil Society Index

- International comparative and participatory approach to increase knowledge about civil society and improve the social impact of civil society,
- currently performed in 70 countries
- coordinated by CIVICUS Alliance for Citizen Participation, Johannesburg (600 member organisations in 110 countries)
- German partner: MAECENATA Institute, Berlin
The CIVICUS Civil Society „Diamond“

The Civil Society Status Diamond for Romania:

Sabine Reimer Maecenata Institut für Philanthropie und Zivilgesellschaft Workshop 16.02.04
Subdimensions and selected indicators of „Structure“ (I)

1) **Breadth of engagement**

- 34% voluntary engagement (survey 99)
- 1-4% health related self help (Borgetto 02)
- 6-9% among chronically ill (Borgetto 02)
- 70 000-100 000 self help groups
- about 40-60 000 in health
- of these only 300 are active at federal level
- 250-300 self-help contact and support centers
Structure (II):
other subdimensions and indicators

2) **Depth of engagement:**
Amount of private resources: money, time

3) **Diversity:** Member structure, regional distributions

4) **Level of organisation, infrastructure**
Umbrella organisations, self regulation, capacity building in the arena: training, international networks

5) **Networks within the arena:** Communication, exchange of information, cooperation, joint purchasing, strategic

6) **Capacities/Resources:** Financial, personnel, technical, facilities, informational
Subdimensions of „environment“

1) Political environment
2) Legal environment (see presentation of C Mühr)
3) Sociocultural environment
4) Socioeconomic support

Total financial resources for health related self help groups in 2001: 436 Mio. Euro

- private households and organisations: 416 Mio. Euro
- social health insurance: 20 Mio. Euro
- States and municipalities: not included in this source (ca. 10 Mio. Euro, decreasing in most states)

Subdimensions of „Values“

1) **Internal democratic order and rules**
   - Membership representation, consultation, minority vote
   - Activities to strengthen..

2) **Transparency**
   - Flow of information in the arena and within organisations
   - Internal corruption
   - Transparency of finances

3) **Tolerance**
   - Within the arena, within organisations
   - Activity to strengthen tolerance in the arena, organisations, among political stakeholders and citizens

4) **Non-violence, 5) gender democracy, 6) poverty reduction**
Subdimensions of „Impact“

1) Impact on political decision-making
2) Holding government and business accountable
3) Responsiveness to societal interests
4) Supporting citizens
5) Responsiveness to social needs

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Discussion and conclusions (I)

The patient civil society in Germany:

• Rich and heterogeneous arena
• With recent increase in organisational level
• With strong values of autonomy and self-help
• Recent increase of self-regulation and external regulation
• Recent enlargement of political and legal space
• Recent professionalisation (and funding) for public patient information services
Discussion and conclusions (II)

- Recent increase of political advocacy activities and political impact (see presentations of Muehr, Wörz and Isenberg)
- Increase of social health insurance funding but decrease of funding from federal states and municipalities
- Increase in responsibilities does not (yet) go along with more financial, personnel resources
- Increased requirement to cooperate in political advocacy while competing for economic resources
Discussion and conclusions (III)

- The CIVICUS Civil Society Index is a useful analytical framework and tool to study the subsector of patient civil society at national level and international level.
- Adaptation to national characteristics (federalism, social health insurance) is required.
- Operationalisation for patient civil society is required.
- For comparative purposes, a more patient specific template would be required.
- Patchy written data + information ...
... This overview report as a possible start of the full participatory CIVICUS Civil Society Index process?

1. Secondary Data Review & Overview Report

2. Training of National Index Teams

3. Meeting of National Advisory Group

4. Primary Research (Reg. Stakeholder consultations; media review, etc.)

5. Data Analysis & Scoring

6. National Workshop

Country Report

Identification of Civil Society Strengthening Initiatives
Download of this presentation:
http://mig.tu-berlin.de

Further information on the CIVICUS Civil Society Index Project:
www.civicus.org

Health care in transition profiles et al.