

# **Patients', Self-help and Disabled People's Organisations in the Policy Process**

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# Outline

- The strength of Patients' interests in the political system
- Presentation of an analysis of Patients', Self-help and Disabled People's Organisations on the German lobbyist 1993 and 2004
- Latest developments of patients rights in German health care policy
- Conclusions

**In political science theory patients interests are considered to be difficult to organise and to have no veto power for mainly two reasons:**

- patients have no important resources to withhold which are necessary for the functioning of a society
- illness is mostly a transitory state which does not give people an incentive to join an organised group

(Offe 1969)

# Lobbyist (Public-List) for the German Bundestag

- Associations are listed in the lobbyist which represent interests to parliament or government. The lobbyist contains the following information:
  - Name and address of the organisation
  - Composition of the leadership
  - What are the interests to be represented?
  - members (number)
- Currently there are roughly 1700 associations on the list (representing a broad spectre of society)

# Method

- Searching the lobbyist for related catchwords (*patients, self-help-groups and disabled people*) for the years 1993 and 2004
- Exclusion of those organisations which do not claim to represent the interests of health related problems (e.g. self-help-group for the annual income-tax declaration)

# Number of Organisations on the Lobbyist

|             | Patients' interest groups | Disabled People | Self-help groups |
|-------------|---------------------------|-----------------|------------------|
| <b>1993</b> | 5                         | 24              | 11               |
| <b>2004</b> | 13                        | 34              | 14               |

# Number of members on the lobbyist

|             | Patients' interest groups | Disabled People | Self-help groups |
|-------------|---------------------------|-----------------|------------------|
| <b>1993</b> | 20,400                    | 2.8 mill.       | 256,000          |
| <b>2004</b> | 98,700                    | 3.5 mill.       | 409,000          |

# „Original“ patients' organisations and „advocacy“ organisations

|      | Patients' interest groups         |                          |
|------|-----------------------------------|--------------------------|
|      | „original“ patients organisations | „advocacy“ organisations |
| 1993 | 4                                 | 1                        |
| 2004 | 9                                 | 4                        |



## **„advocacy“ organisations in 2004**

- Federal Association of Hospital Pharmacists
- Association of Hospital Directors in Germany
- Federal Association of Managed Care
- Federal Association of Ambulatory Diabetologists

# **SHI–Modernisation Act and patients‘ participation (I)**

- The latest health care reform (coming into force mainly in January 2004) strengthened the participation of patients‘ in several respects
- An important component was the inclusion of patients‘ representatives into the system of self-government (which until then only consisted in representatives of financiers (SHI-funds) and the providers of health care)

# SHI–Modernisation Act and patients‘ participation (II)

- The central institution of self-government is the so called *Joint Federal Committee* (Gemeinsamer Bundesausschuss) which has many competencies concerning the benefit catalogue of the Statutory Health Insurance, quality-assurance and evidence based patient information
- 4 patients‘ organisations are eligible to send representatives to the Joint Federal Committee. These 4 organisations were determined by the Federal Ministry of Health and Social Security. Patients‘ representatives have no voting right in the Committee

# Conclusions

- There is a strong increase both in the number of organisations and members in relation to the interests of patients, disabled people and self-help-groups
- The observable strengthening of patients rights by the government is very likely influenced by this increase
- A positive side-effect of the change in the illness spectre towards chronicle illnesses seems to be that patients' interests become easier to organise
- Legitimacy is an important ressource in the policy process and can compensate for power ressource