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)
Lobbylist (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 Lobbylist

<table>
<thead>
<tr>
<th></th>
<th>Patients’ interest groups</th>
<th>Disabled People</th>
<th>Self-help groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>1993</td>
<td>5</td>
<td>24</td>
<td>11</td>
</tr>
<tr>
<td>2004</td>
<td>13</td>
<td>34</td>
<td>14</td>
</tr>
</tbody>
</table>
### Number of members on the lobbyist

<table>
<thead>
<tr>
<th></th>
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<th>Disabled People</th>
<th>Self-help groups</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1993</strong></td>
<td>20,400</td>
<td>2.8 mill.</td>
<td>256,000</td>
</tr>
<tr>
<td><strong>2004</strong></td>
<td>98,700</td>
<td>3.5 mill.</td>
<td>409,000</td>
</tr>
<tr>
<td>Year</td>
<td>&quot;original&quot; patients organisations</td>
<td>&quot;advocacy&quot; organisations</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------</td>
<td>--------------------------</td>
<td></td>
</tr>
<tr>
<td>1993</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>9</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
„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 financers (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 chronic 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 ressources