

European Communities

EUROPEAN PARLIAMENT

Working Documents

1983 - 1984

8 March 1984

DOCUMENT 1-1518/83

REPORT

drawn up on behalf of the Committee on the Environment,
Public Health and Consumer Protection

on self-help groups in health care

Rapporteur: Mr D. EISMA

PE 87.317/fin.
Or Ne

English Edition

At its sitting of 8 July 1982, the European Parliament referred the motion for a resolution tabled by Mrs VAN HEMELDONCK (Doc. 1-499/82) pursuant to Rule 47 of the Rules of Procedure to the Committee on the Environment, Public Health and Consumer Protection.

At its meeting of 17 March 1983 the committee decided to draw up a report and appointed Mr EISMA rapporteur.

It considered the draft report at its meetings of 26 January and 22 February 1984 and at the latter meeting adopted the motion for a resolution by 7 votes to 5.

The following took part in the vote: Mr Collinā, chairman; Miss Hooper, vice-chairman; Mr Eisma, rapporteur; Mr Alber, Mr Bombard, Mr Ghergo, Mr Johnson, Mr Mertens (deputizing for Mrs Lentz-Cornette), Mr Provan (deputizing for Mr Forth), Mrs Schleicher, Mrs Seibel-Emmerling and Mrs Viehoff (pursuant to Rule 93(2)).

The committee decided to apply the procedure laid down in Rule 34 to this report.

The report was tabled on 1 March 1984.

The deadline for tabling amendments to this report will be indicated in the draft agenda for the part-session at which it will be debated.

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The Committee on the Environment, Public Health and Consumer Protection hereby submits to the European Parliament the following motion for a resolution together with explanatory statement:

A.

MOTION FOR A RESOLUTION

on self-help groups in health care

The European Parliament

- having regard to the motion for a resolution on self-help in the medical field (Doc. 1-499/82),
 - having regard to its resolution on voluntary work¹,
 - having regard to its resolution on a European charter for patient's rights²,
 - having regard to Recommendation No. (80) 4 of the Committee of Ministers of the Council of Europe on the patient as an active participant in his own treatment,
 - having regard to the report on a workshop held in Höhr-Grenzhausen on 7-9 June 1982 by the Hamburg Information Centre under the auspices of the European Office of the World Health Organization,
 - having regard to the report by the Committee on the Environment, Public Health and Consumer Protection (Doc. 1-1518/83),
- A. whereas since this resolution deals only with self-help groups, the general concept of individual self-care and self-help remains outside its scope;

¹ OJ No. C10, 16 January 1984, p.288

² Resolution of 19 January 1984

- B. whereas self-help groups came into existence through the discovery that problems can be better solved with the help of those who share them,
- C. whereas, partly because of the crisis in the welfare state, our society has a great need of new forms of support, sharing and solidarity,
- D. whereas self-help groups aid processes that are beneficial to health and provide a necessary supplement to traditional health care,
- E. whereas in the training of professionals insufficient attention is given to dealing with active patients and self-help groups and that such patients and groups receive too little attention within the health service,
- F. whereas there is increasing interest in these groups among the public and governments in the EEC countries,
- G. whereas self-help groups should not be supported by governments only in the interests of economy but also because self-help has an intrinsic value,
- H. whereas self-help groups help form a bridge between the empirical judgement of the ordinary citizen, whether or not he is a patient, and professional expertise (of doctors, hospitals and social welfare institutions), and can therefore promote the efficiency and effectiveness of cooperation between the patient and professionals,
- i. whereas self-help groups stand for the active participation of the citizen, whether or not he is a patient, in maintaining, improving and restoring his or her own health and consequently is in line with the emancipatory trend whereby people want to take responsibility for their own lives and with attempts to cut costs, to encourage a responsible use of medical services and to counteract excessive medical consumption,

- J. whereas the specific development and creativity of the self-help groups must be encouraged, and whereas this must be expressed by developing an appropriate financing system and by extending financial resources to cover self-help organizations,
1. Calls on the Commission to frame a policy for self-help and its promotion with attention being given to a policy on voluntary work;
 2. Is of the opinion that an international exchange of information and experience can contribute to the objectives mentioned above, particularly at European level, and calls on the Commission to invite representatives of self-help groups to speak at EEC level about their common problems;
 3. Requests the Commission to incorporate research into self-help into its fourth research and development programme in the field of medical and public health research - concerted action - and, in relation to preventive medicine, to allocate an appropriate percentage of the total research budget to research into self-help and to involve existing self-help centres in the relevant preparatory work;
 4. Calls on the Commission to involve representatives of the self-help organizations in the appropriate Community-level meetings of those professionally responsible for health care;
 5. Calls on the Commission to make financial support available now for accommodation for meetings, staff, telephone costs, subsistence allowances and other organizational expenditure, in order to set up a European meeting place where representatives of self-help groups could meet regularly to exchange experiences;
 6. Calls on the Commission to support pilot schemes, giving priority to self-help projects in areas where they are developing slowly or are wholly non-existent;

7. Calls on the Commission to draw up a communication to the Council of Ministers as a result of its activities in connection with self-help groups, on new developments in health care and the place of self-help and self-care, in the context of relations between society and sickness;
8. Instructs its President to forward this resolution to the Commission, the Council and the governments of the Member States.

EXPLANATORY STATEMENT

I. Definition of the subject

1. Self-help is a very broad term and can cover a wide range of ideas, so it is necessary to define it. In ideological terms, self-help signifies people's ability to take charge of their own lives. There can be no doubt that in recent years there has been an increasing demand throughout the world for self-help in this sense (the surge towards democracy, liberation movements, etc.).

2. Self-help can be relevant to many areas of daily life: housing, environment, health and welfare - areas where people have felt the need to group together to feel stronger. In this report, we shall confine ourselves to self help in health care.

3. In the field of health and welfare the self-help trend has many facets and is connected with other important developments: new concepts of illness, the movement towards participation, liberalization in dealing with emotions, programmes for a healthy life-style etc. The professional system is also continually encouraging more varied forms of self help: insulin injections for diabetics, measuring one's own blood pressure, preparing one's own food in hospital, etc.¹

4. We regard these more general trends in our society as being of exceptional importance. Consequently we call on the Commission to give the necessary attention to them, especially as no complete picture of the range of self-help groups in the Member States is available: thus there are a large number of self-help groups in the Federal Republic of Germany, the United Kingdom, the Netherlands and (North) Belgium, but little is known of self-help groups in France, Italy and Greece, for example.

5. In this resolution we confine ourselves to discussing self help in the context of more or less organized groups. For simplicity's sake we shall use the term self-help groups².

6. It is however useful to make the following distinction:
- a. autonomous self-help groups: are relatively small groups of people, who work out shared problems together. Self help groups form around very specific and definite problems: breast cancer, diabetes, unmarried motherhood, drug addiction, etc. In self-help groups people follow each other's example and they learn from others' experience of sickness and their acquired knowledge. As a rule no professionals take part in the group process.
 - b. self-help organizations: these are organizations that link self-help groups. They provide services for individual groups and often take on the role of watching over their outside interests.

7. For self-help groups in the strict sense giving help is their prime function. A distinction must be made between them and organizations that defend patients' interests, which in fact came into existence in another context and are concerned with watching over interests, representation and extending facilities, whether or not for a particular category. Nevertheless there are self-help organizations that, in addition to organizing local self-help groups, also act to defend interests. They therefore have a double function.

8. Self-help groups fulfil several functions. Only one can be dealt with here. Dealing with most non-medical aspects of (physical or mental) illnesses or handicaps, especially in a chronic form, presents the welfare system with an impossible task. If one were to attempt to have this human need relieved by the professionals, this would engender a system of assistance on a gigantic scale, in which it is doubtful whether the desired results would be achieved in any case.

9. It has been shown that self-help groups provide a cheap and efficient solution to this problem. In your rapporteur's view, this alone would justify the Commission's giving attention to these groups. To be really effective, the development of a policy for self-help groups at European level should be given high priority.

II. Self help and the professionals

10. On the basis of research it can be established that professional helpers are involved in a majority of self-help groups, either in setting them up, encouraging them or in methodically supervising them. On the one hand a minority of self-help groups have an anti-professional composition on the other a few professionals are opposed to what they regard as non-professional medicine and/or help. In most cases particular activities are seen not as being in competition with but as complementing each other.

11. Self-help gives a type of back-up that professionals for various reasons are unable to give. Professionals cannot avoid maintaining a certain distance in order to carry out their work efficiently. Since the emergence of patients' associations doctors have given more attention to the emotional and/or psycho-social problems that almost always accompany physical health problems.

12. In addition, existing forms of help often lack continuity (they cater purely for medico-technical care in crisis situations): through self-help the chronically sick receive permanent supervision, with the result that all side-effects of their illness can be taken into account. Often the patient finds himself powerless when confronted with doctors' decisions: self help gives him greater awareness as a consumer of health care. Finally, while the technical means become ever more expensive for the individual and society, self help is democratic and accessible to everyone.

13. Your rapporteur thinks it important to work for optimum relations between laymen and professionals. Up to now however, too few professionals have been convinced that their treatment can be usefully supplemented by self-help. Good relations between laymen and professionals would entail sick people being directed towards patients' groups by doctors, members of self-help groups who wish to visit someone who is ill or has just had an operation having access to hospitals, etc.

14. Of professionals (doctors, psychiatrists, psychologists, social workers, lawyers and even spiritual advisers) it may be expected that they would support the organization of self-help groups and would give advice on their fundamental approach³.

15. Mention should here be made of research carried out in Maastricht: a form of cooperation has been developed where patients are helped by a doctor and a fellow sufferer⁴. At the same time an analysis is made of (the possibilities and limitations of) cooperation between doctors and patients' organizations⁵.

16. Self-help groups develop new techniques and give attention to other stages and aspects of illnesses that were formerly neglected or ignored. Self help must nevertheless not be seen as alternative medicine, but as a valuable contribution to the health care system, and professionals should recognize it as a legitimate source of help⁶.

III. Government policy on self-help groups

17. There is an increasing tendency for national governments to form a policy on self-help groups. In all countries where self-help groups are to be found governments have tried to obtain means (such as workers and finance) to achieve their goals. This was mostly achieved by the application of existing regulations. There was no question of policy actively directed towards self-help groups, but there have recently been changes here⁷.

18. Outside the European Community it is North America that is of the greatest importance because it was there that self help originated and it is there that it is the most developed. One of the most important manifestations is the self-help clearing houses. These are bodies that are specifically directed towards self help groups, with the aim of informing the public and of bringing together the groups, the professional helpers and the policy. These clearing houses are to be found in both the United States and Canada and have also been set up in a number of Community States.

19. These are not the only measures that have been taken. The Canadian government for example decided - after thorough research - to give active support to self-help groups. This involved among other things the setting up of an administrative unit within the government, specially for the promotion of self help, which among other matters devotes itself to media policy (newspapers publish the addresses of self-help groups, special television films have been prepared on the subject, etc.)

20. A number of social and policy developments in the Member States should also be mentioned. In the United Kingdom there is an official responsible for liaison between self-help groups and the ministries concerned. In the FRG in one federal state (including Hessen) a subsidy system for self-help groups has been established, while in another (Hamburg) a clearing house has been set up. In the Netherlands statements on policy have laid positive emphasis on the citizen's responsibility for his own health and a special section for financing self-help groups has been set up within a semi-public fund. Finally, in Belgium, a clearing house in Flanders is being financed by the government; no initiative is known in Wallonia.

21. The Belgian situation illustrates the dividing line that seems to exist between the Northern, Germanic countries and the Southern, Latin countries. In the latter (France, Italy and Greece among others) similar self-help groups do exist but show little sign of active life. Consequently they receive little scientific and political attention, which consequently strengthens the impression that these lay initiatives occur less frequently. A central identification point in each country could produce some changes here.

22. In some countries there are possibilities of recruiting government paid manpower in the social sector; little use is made of this however because there is an enormous lack of information and 'bureaucratic' help from the government⁸.

23. At the level of international policy self help has come under discussion in the last few years in many international or supranational bodies. In 1980, the Committee of Ministers of the Council of Europe formulated a policy recommendation for the governments of the Member States on the patient as an active participant in his own treatment⁹, in which it was urged that encouragement should be given to self-help and patients groups. The wish was expressed that the education and training of professional helpers should also include cooperation with these kinds of groups and that patients' organizations should be able to influence public health policy if they so wished.

24. None of the institutions of the European Community, on the other hand, has given any attention to the question of self help. Self-help groups are regarded merely in terms of the studies devoted to major risk groups such as alcoholics, the elderly, migrant workers and their families and so forth. Under the third programme on health research of August 1980¹⁰, prevention and medical care inside and outside the hospital are among the subjects being studied. This shows that the Commission is aware that health is not only a question of doctors, medical equipment and hospitals, but also of man's well being in his environment. A person's natural surroundings can have a favourable influence on the healing process^{11,12}.

25. WHO-Europe has made policy recommendations to encourage self help within its region, so as to offer the necessary opportunities¹³. The WHO proposes to set up referral centres in a number of southern countries. In the national states it is now an established fact that groups have now won the right, in various ways, to receive subsidies. This special support cannot be withdrawn; there is rather a likelihood of general support being granted for self-help groups.

26. Resource centres should be made available for small geographic units. The public could apply to them directly for information and the groups could make use of meeting rooms and secretarial facilities there. Practical, material support is important here.

27. In larger geographic units (federal state, state) it is proposed that a clearing house should be set up. In addition to an information and documentation centre for all those interested, such a clearing house would also provide facilities for meetings between:

- 1) self-help groups, so they could adopt common positions or exchange experiences;
- 2) self-help groups and the administration;
- 3) self-help groups and experts; and
- 4) self-help groups and professional helpers.

The choice of 'open' means of implementing policy guarantees the autonomy of those that make use of them and is appropriate in view of the great variety of groups.

28. It should, moreover, be mentioned that an information centre for research into self help is already operating in Europe. It is partly financed by the WHO and is presently established in Hamburg, but from 1984 will be in Louvain. The original aim was to provide for an exchange of views on experiences in research, but changes have gradually been introduced, so that there are an increasing number of discussions on self-help programmes worked out by self-help groups. National self-help groups are also brought into contact with one another and international working meetings and training sessions (duo training) are organized.

IV. Conclusions

29. Seeing that all EEC Member States are also members of the WHO it would be desirable to work out a common policy. A study should be made of types of cooperation between professionals and self help groups¹⁴. At policy level there should be a survey of what Member States' governments are already offering by way of support for self help and whether they should be encouraged to extend their legislation on the subject.

NOTES

1. LAFAILLE, R., and others Self-Help Techniques, K.H. Tilburg
2. There is considerable agreement on this definition of self-help groups in the works on the subject. See inter alia:
 - KATZ, A.H. and E.I. BENDER, The Strength in Us. Self-Help Groups in the Modern World, New York, Franklin Watts, 1976
 - MOELLER, M.L., Selbsthilfegruppen, Reinbeck bei Hamburg, Rowohlt Verlag, 1978
 - ROBINSON, D. and S. HENRY, Self-Help and Health: mutual aid for modern problems, London, Martin Robertson, 1977
 - GARTNER, A. and F. REISSMAN, Self-Help in Human Services, New York, 1977
 - HARBERDEN, P. van and R. LAFAILLE, Zelfhulp, een nieuwe vorm van hulpverlening? Vuga, The Hague, 1978
 - BRANCKAERTS, J., Dossier Zelfhulp, in : Sociaal, no. 14/12/81
3. In this connection, see HOEKENDIJK, L., Werboek Zelfhulp, Ede, published by Zomer & Keuning, 2nd impression 1981
4. BREMER SCHULTE, M., Samen beter worden: nieuwe samenwerkingsvormen tussen patiënt en hulpverlener, Alphen a/d Rijn, Samson 1980
5. Idem, Medical Education in Relation to Self-Activity of Patients, strategies for change, in: Kickbusch and hatch, Self-help and Health, London 1983 (WHO publication 1983)
6. LEVY, L., Processes and Activities in Groups, in: M. Lieberman and L. Borman, Self-Help Groups for coping with crisis, San Francisco, Jossey Bass Publishers, 1979, quoted by J. BRANCKAERTS in Zelfhulp, een inleiding tot het veld en de literatuur, Sociology Department, Katholieke Universiteit van Leuven, February 1983, pp. 5200-10
7. BRANCKAERTS, J., and others, Het zachte verzet, Deventer/Deurne, van Loghum Slaterus, 1982

8. In Belgium for example the 'Third Labour Circuit' (Troisième circuit de travail) allows for the recruitment of those affected by structural long-term unemployment by public or private promoters for activities of general interest in the non-commercial sector, i.e. that public or social use or of cultural importance. Costs are fully covered by the State
9. Recommendation No. (80) 4 by the Committee of Ministers of the Council of Europe on the patient as an active participant in his own treatment
10. Council Decision of 17 August 1982 adopting a sectoral research and development programme of the European Economic Community in the field of medical and public health research - concerted action - (1982 to 1986), (82/616/EEC), OJ L 248 of 24 August 1982, p. 12
11. See in this connection G.E.R.M., L'hôpital à sa juste place, in: La Revue Nouvelle, No. 4, 1976, pp. 486 ff
 RIXHON, N., Le malade est inconnu, *ibid.*, p. 382
 FRANCK, R. and F. GOBBE, Une alternative pour une autre médecine, in: La Revue Nouvelle, No. 9, 1978, pp. 160 ff
 CHEVALIER, P. and X. ROUSSEAU, Témoignages, *ibid.*, p. 163
12. See also the WHO's definition of health as a state of complete physical, mental and social well being and not simply as the absence of illness
13. WHO, Europe, Mutual Aid: From Research to Supportive Policy, Report on a Workshop, Höhr-Grenzhausen, 7-9 June 1982
14. On doctor-patient relations, see also: 'The patient's rights', basic manifesto and information, second day of action by the working party Doorbraak-Gezondheidszorg, Universitaire Fakulteiten Sint-Ignatius Antwerpen, 5.2.1983

MOTION FOR A RESOLUTION DOCUMENT 1-499/82

tabled by Mrs VAN HEMELDONCK pursuant to Rule 47 of the Rules of Procedure
on self-help in the medical field

The European Parliament

- A. having regard to Article 235 of the Treaty establishing the European Economic Community and Council decision 80/344/EEC of 18 March 1980 adopting a second research programme in the field of medical and public health research,
 - B. having regard to the recommendations on health and medical self-help drawn up by the World Health Organization at its meeting of 3-6 December 1980 in Copenhagen,
 - C. having regard to Recommendation No. (80) 4 of the Committee of Ministers of the Council of Europe on the patient as an active participant in his own treatment,
 - D. having regard to the growing number of medical self-help groups in the Member States of the Community,
 - E. whereas the Member States must cooperate more closely with one another in order to pursue a more effective policy in the field of hygiene and public health, and whereas the Commission must play a stimulating role in this process,
- 1. Calls on the Commission to carry out a study on self-help in the field of hygiene and public health in the various Member States;
 - 2. Instructs its President to forward this resolution to the Commission and to the governments of the Member States.